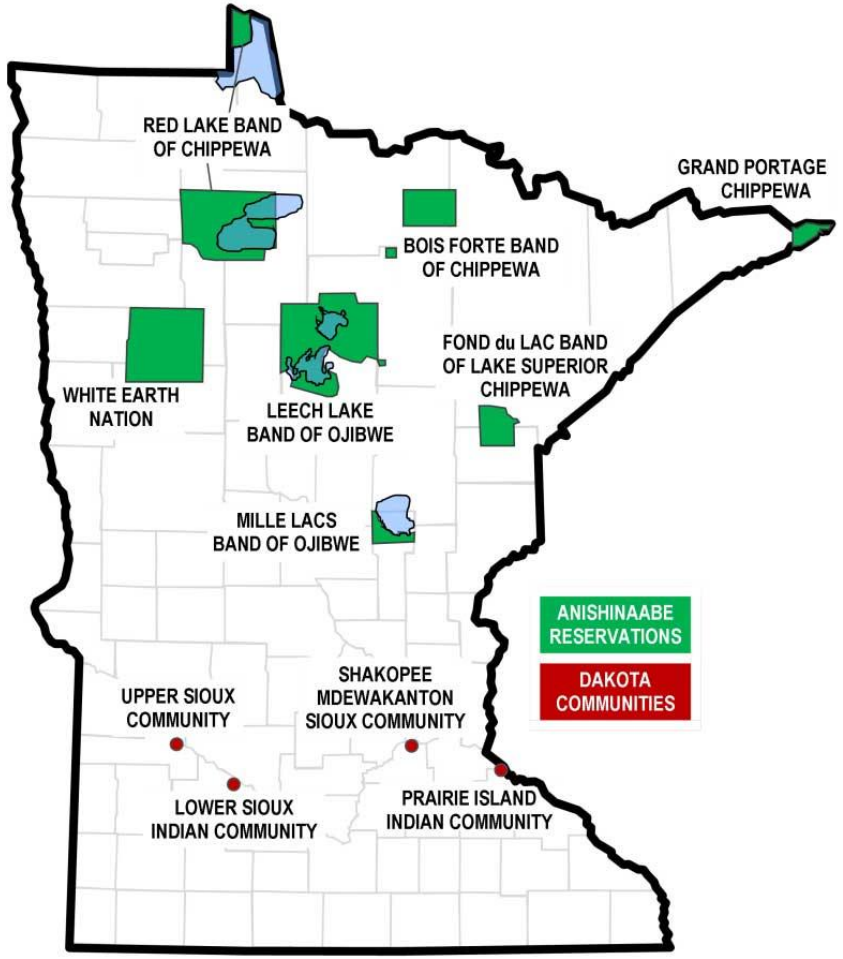
# CYSHN Condition Follow-up Community of Practice

November 13, 2025

# Tribal-State relations acknowledgement statement

The State of Minnesota is home to 11 federally recognized Indian Tribes with elected Tribal government officials. The State of Minnesota acknowledges and supports the unique political status of Tribal Nations across Minnesota and their absolute right to existence, self-governance, and self-determination. This unique relationship with federally recognized Indian Tribes is cemented by the Constitution of the United States, treaties, statutes, case law, and agreements. The State of Minnesota and Tribal governments across Minnesota significantly benefit from working together, learning from one another, and partnering where possible.

Minnesota Department of Health recognizes, values, and celebrates the vibrant and unique relationships between the 11 Tribal Nations and the State of Minnesota. Partnerships formed through government-to-government relationships with these Tribes will effectively address health disparities and lead to better health outcomes for all of Minnesota.



# CYSHN respect for identities statement

## Short version

We strive to use language that honors individual preferences, recognizing health conditions and disabilities are a natural and valuable part of human diversity. While our program reflects statutory terms like "special," we remain open to changing our language practices based on community feedback to foster belonging, respect, and inclusivity.

## Long version

www.health.state.mn.us/people/childrenyouth/cyshn/about.html#respect

# Agenda

| | |
|---|---|
| 9:00 - 9:15 a.m. | Welcome and announcements |
| 9:15 – 10:15 a.m. | Sickle Cell Disease Presentation |
| 10:15 - 10:30 a.m. | Wrap-up and evaluation |

# MEDSS reminder

How to remove non-reimbursable events off your workflow:

1. Enter the "**Date of assessment or final contact attempt**" (you can use the current date).

2. Check the "**Submit to MDH**" box and "**Save**".

3. Do not enter data in the "Date of first contact attempt" or "Parent/Guardian Contact" field if you are not actually contacting the family. If event is non-reimbursable, these fields are not required to submit even though they have red asterisks.

# Hearing screening referrals

The Public Health Lab has paused sending hearing screening follow-up cases to local public health. Confirmed hearing loss referrals continue to be sent to local public health via MEDSS.

# Onboarding video

https://vimeo.com/1123330124

# Check-in and outreach measures

- Scheduling check-ins for January-February
- Quarterly outreach measures
  - Number of reimbursable referrals sent.
  - Number of reimbursable referrals that received outreach from LPH.
  - Number of reimbursable referrals that LPH initiated outreach within 30 days of referral sent.

| | 2025 Q3 | 2025 Q2 | 2025 Q1 | 2024 Q4 |
|---|---|---|---|---|
| # RR sent to LPH | 32 | 31 | 22 | 28 |
| # RR received outreach from LPH | 32 | 29 | 22 | 28 |
| % RR received outreach from LPH | 100% | 94% | 100% | 100% |
| # RR initiated outreach within 30 days | 32 | 25 | 22 | 24 |
| % RR initiated outreach within 30 days | 100% | 81% | 100% | 86% |

# Infant formula recall

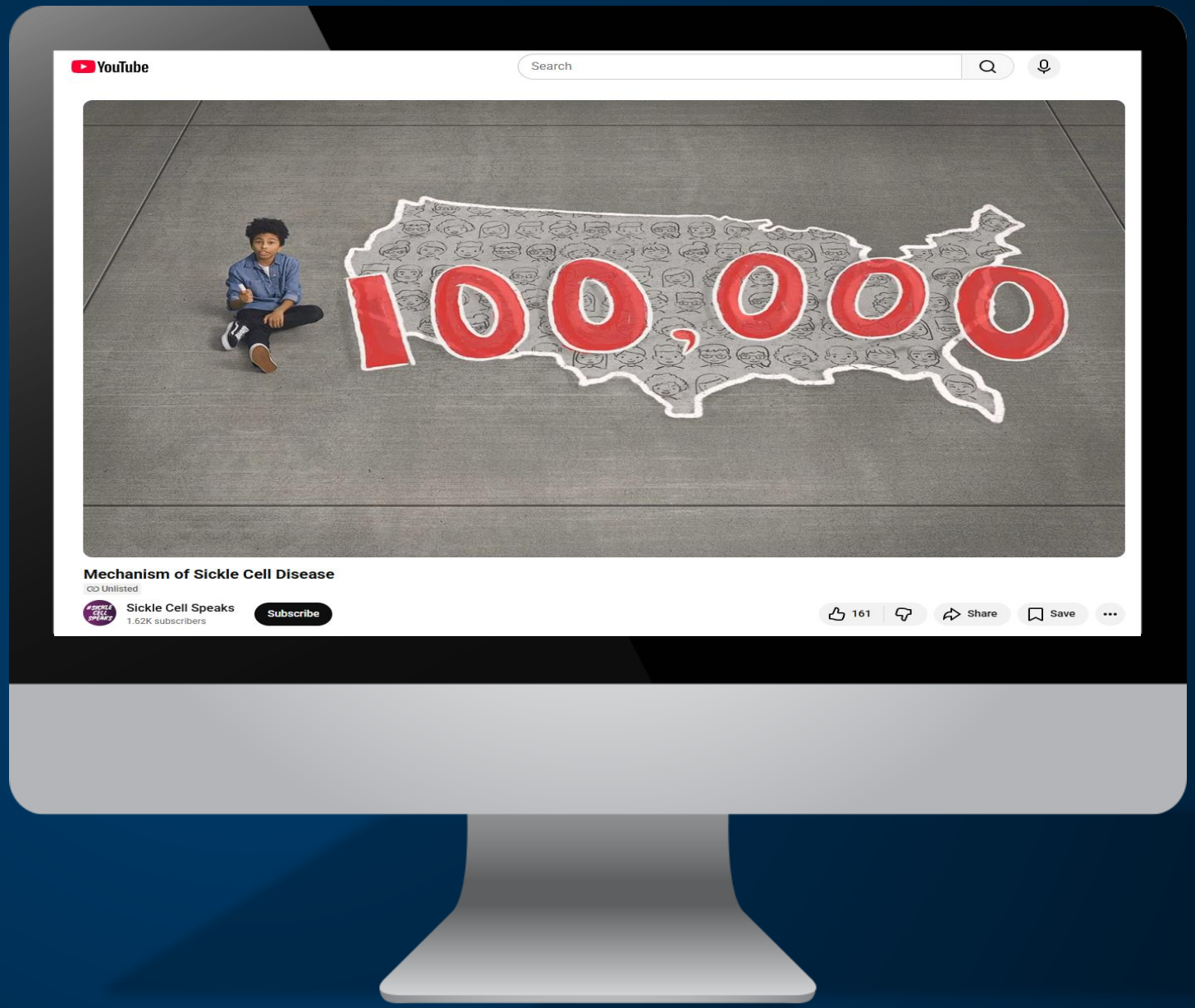
- A multistate outbreak of infant botulism has been linked to ByHeart Whole Nutrition Infant Formula
- Do not use any ByHeart Whole Nutrition infant formula (cans or single serve packets)
- Families should contact their health care provider right away if infants show symptoms such as poor feeding, loss of head control, or weak cry


# Sickle Cell in Minnesota: Beyond the DIS-ease

A presentation by: Amanda Maresh and Rae Blaylark

# Mechanism of Sickle Cell Disease video

https://www.youtube.com/watch?v=HP11Mvx1Vtg&t=263s (4:56)

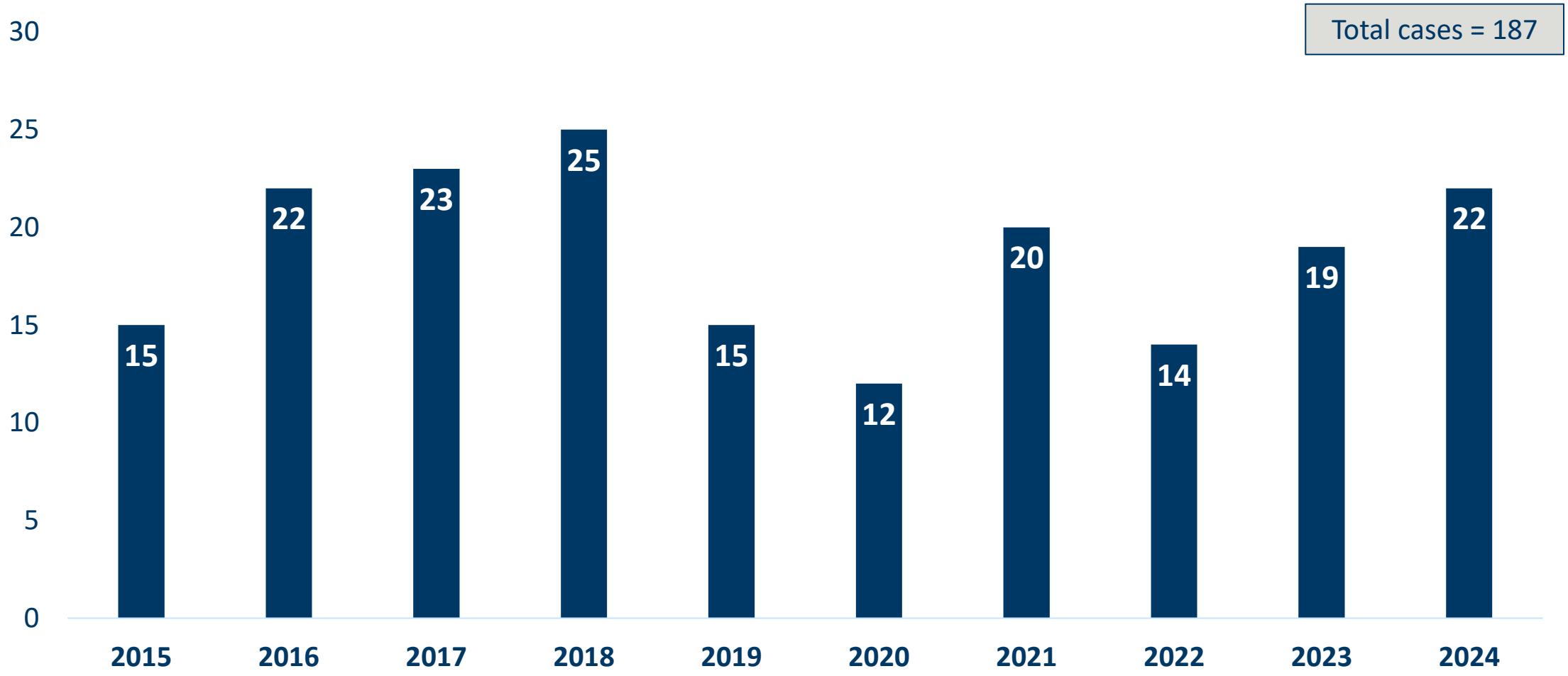


# What is sickle cell disease (SCD)?

- A group of conditions that affect the red blood cells – making them hard, sticky, and shaped like crescent moons or sickles.
- A genetic condition that is present at birth.
- Inherited when a child receives two genes—one from each parent—that code for abnormal hemoglobin.
- Most common in individuals who come from and whose ancestors are from Africa, India, South America, Saudi Arabia, and Mediterranean countries such as Turkey, Greece, and Italy.
- One of the most common hereditary disorders in the United States, affecting approximately 100,000 people.

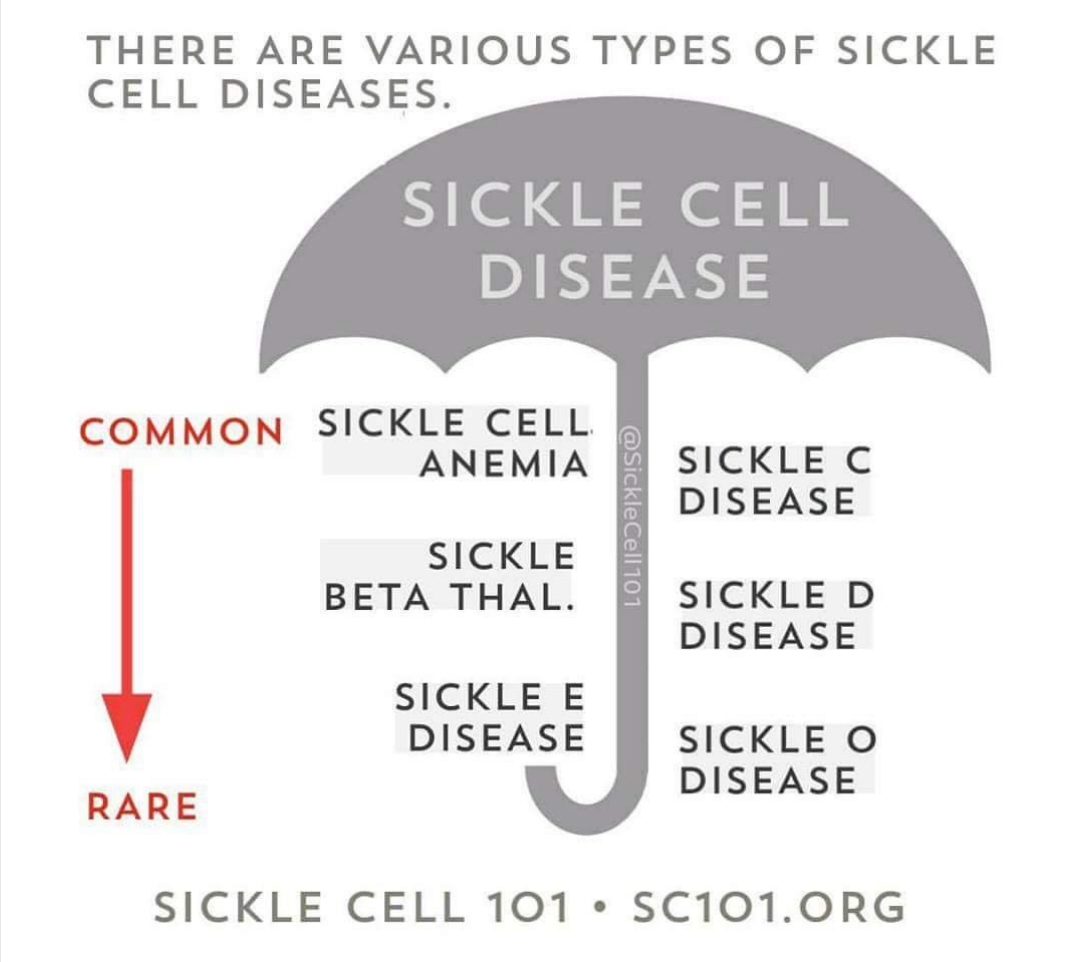
# Sickle cell disease cases

*identified though Minnesota newborn screening 2015-2024*

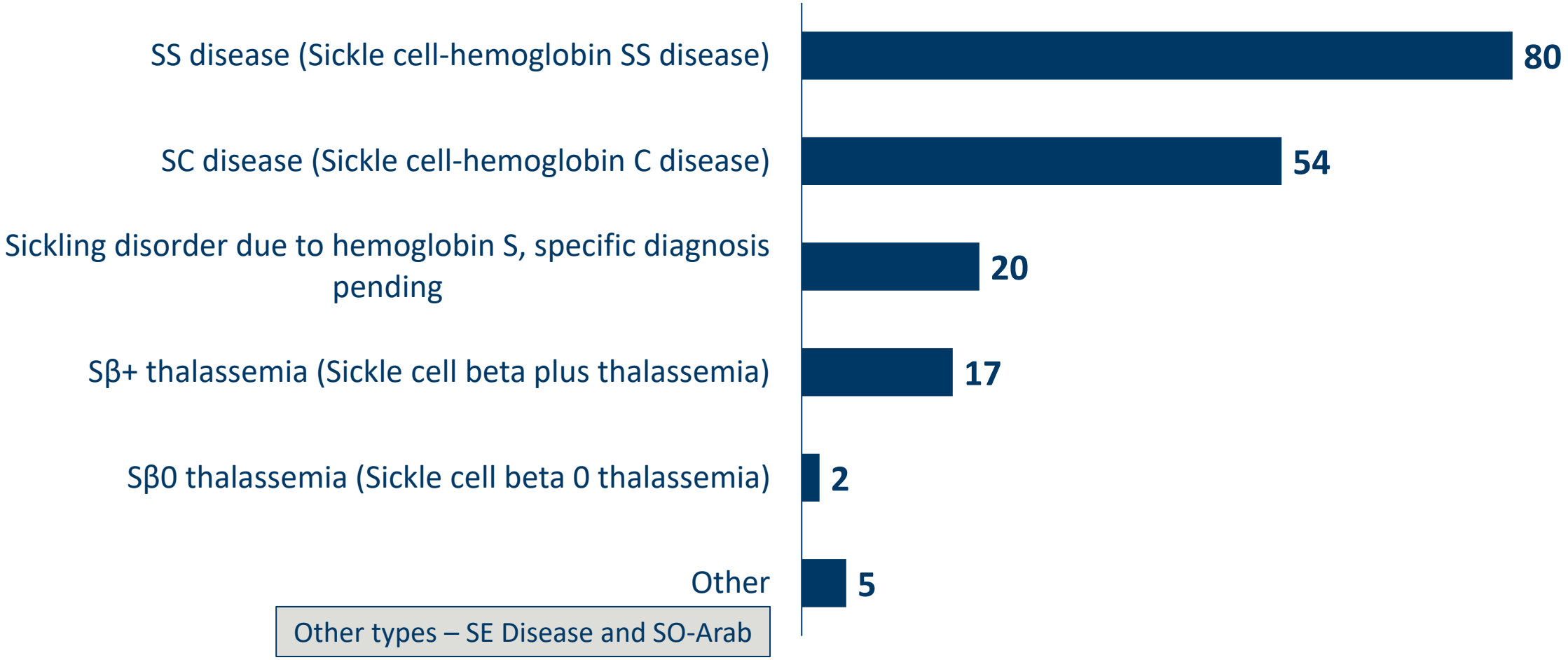


# Types of SCD

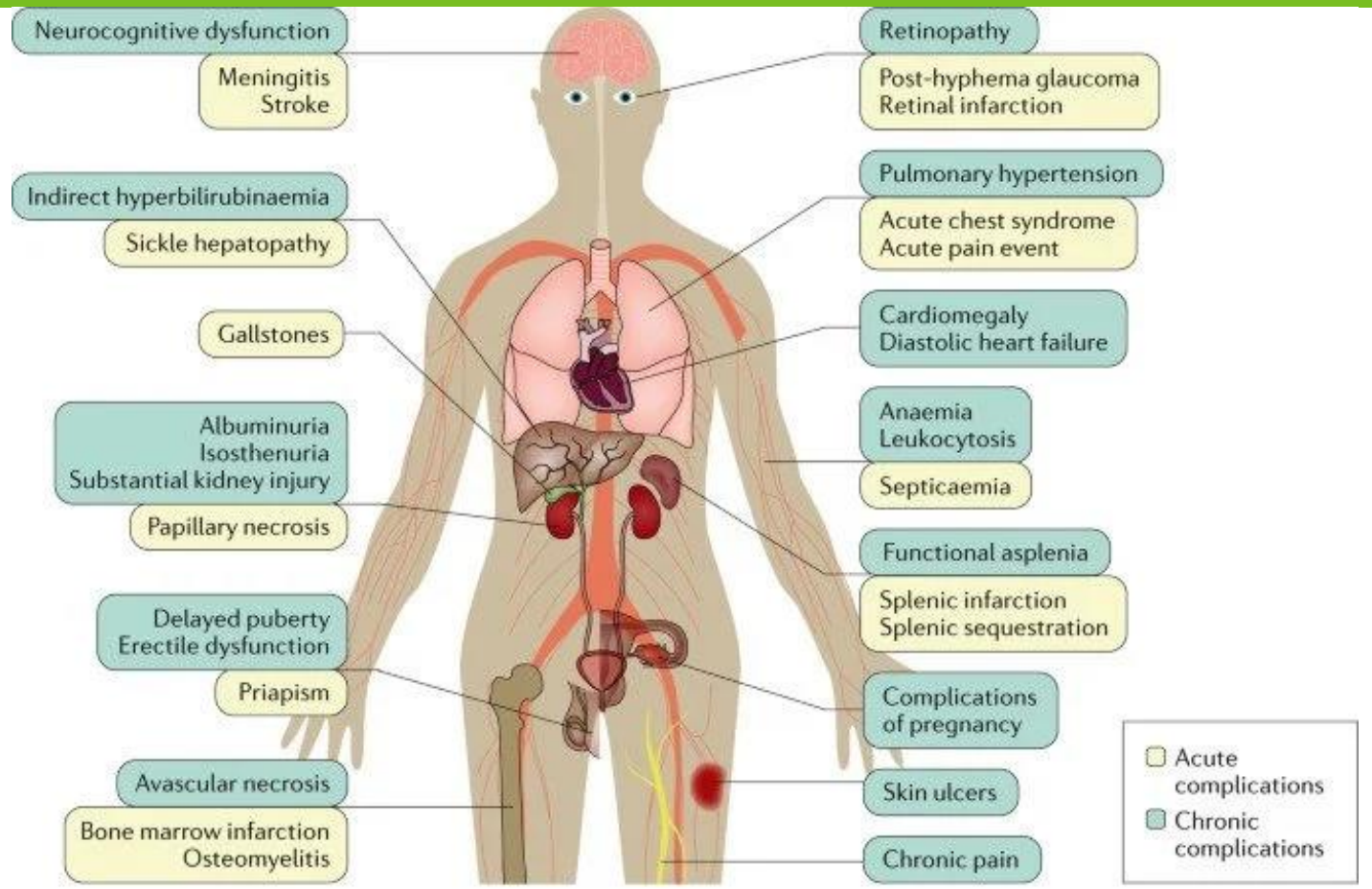
- There are several types of SCD including hemoglobin SS disease (also called sickle cell anemia), hemoglobin SC and hemoglobin S-beta thalassemia.
- The most common type of SCD is hemoglobin SS disease.
- The different types of SCD can vary in severity.



# Types of SCD
*2015-2024*



# SCD symptoms and complications



# SCD complications

- **Pain:** Sickled cells don't move easily through small blood vessels and can get stuck and clog blood flow. This causes pain that can start suddenly, be mild to severe, and last for any length of time. May be referred to as a pain crisis or a vaso-occlusive episode (VOE).
- **Infection:** People with SCD, especially infants and children, are more likely to experience harmful infections such as flu, meningitis, and hepatitis. This is why penicillin is so important to take.
- **Dactylitis (Hand-Foot Syndrome):** Swelling in the hands and feet, often along with a fever, is caused by the sickle cells getting stuck in the blood vessels and blocking the blood from flowing freely through the hands and feet.
- **Sickle Cell Retinopathy:** SCD can affect the blood vessels in the eye and lead to long term damage.

# SCD complications continued

- **Acute Chest Syndrome (ACS):** Blockage of the flow of blood to the lungs can cause acute chest syndrome. ACS is similar to pneumonia; symptoms include chest pain, coughing, difficulty breathing, and fever. It can be life threatening and should be treated in a hospital immediately.
- **Stroke:** Sickled cells can clog blood flow to the brain and cause a stroke. A stroke can result in lifelong disabilities and learning problems.
- **Pulmonary hypertension:** a type of high blood pressure that affects the blood vessels that go from the heart to the lungs. This causes poor blood flow and low levels of oxygen in the blood.

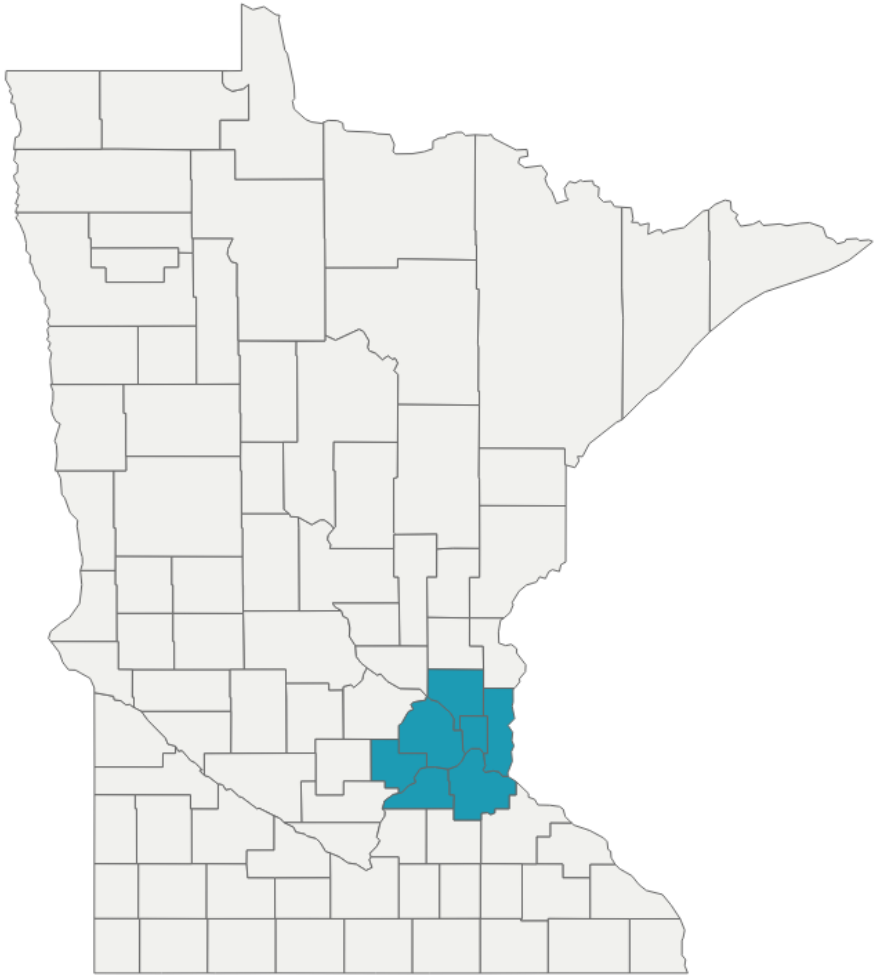
# Clinical recommendations for sickle cell anemia
*(SS Disease or S beta zero thalassemia)*

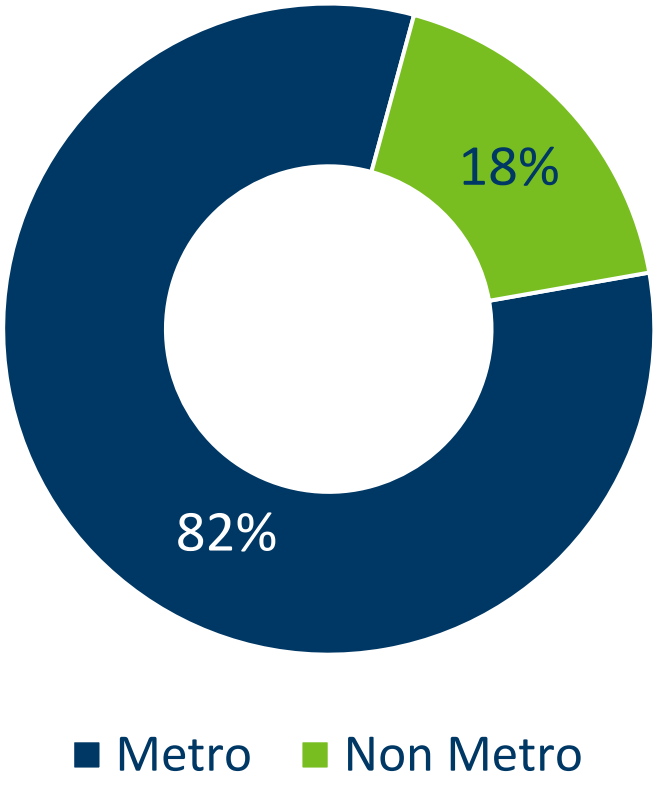
Penicillin (antibiotic prophylaxis) initiated by two months of age

Hydroxyurea initiated at 9 months of age

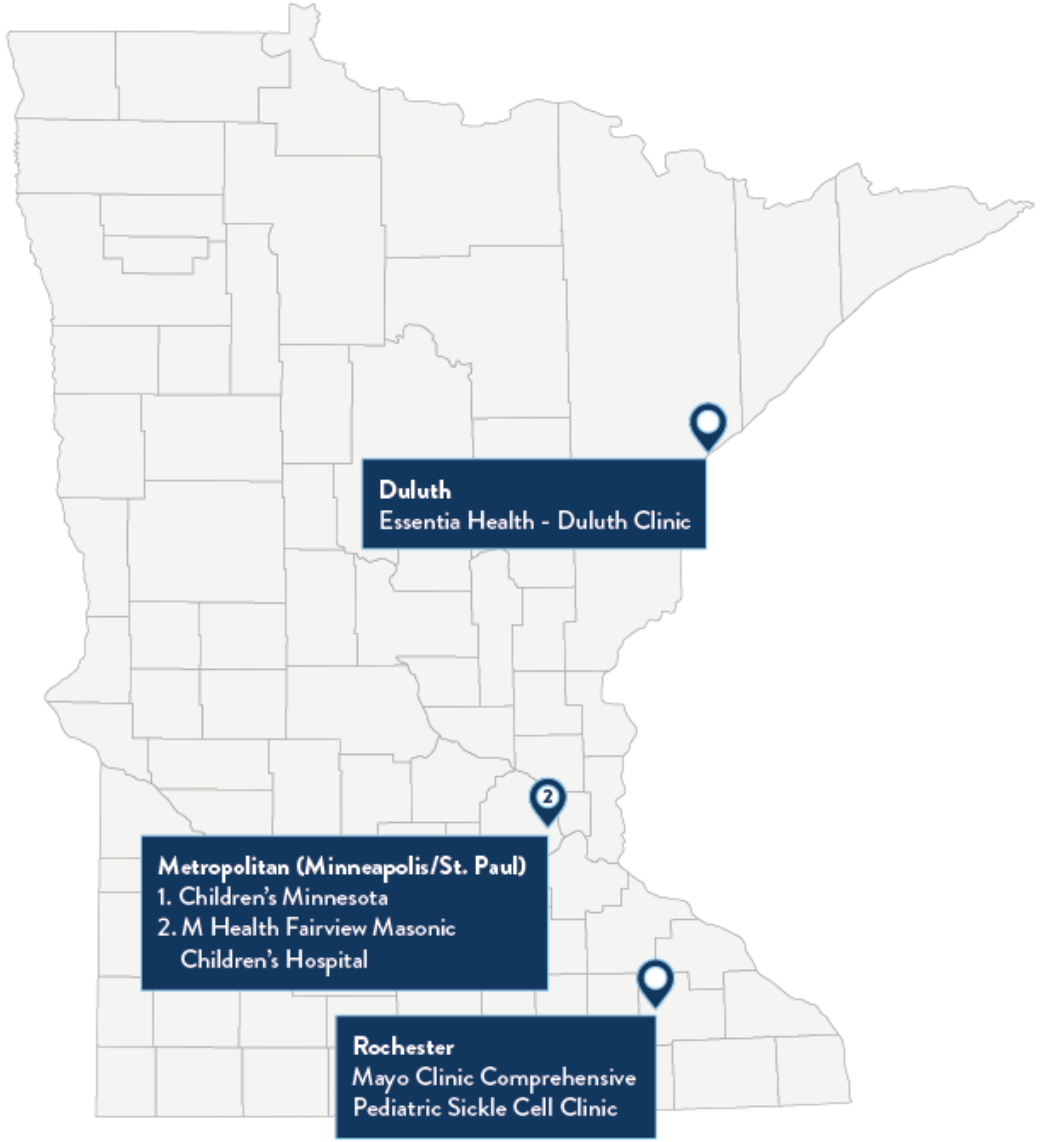
Transcranial doppler ultrasound (TCD) at 2 years, annually up until age 16

# Percentage of children who live in the 7-county metro area
## (*identified though Minnesota newborn screening 2015-2024)*





# Where can children with SCD receive specialist care in MN?




**Metropolitan (Minneapolis/ St. Paul)**

- Children's Minnesota
- M Health Fairview Masonic Children's Hospital

**Rochester**

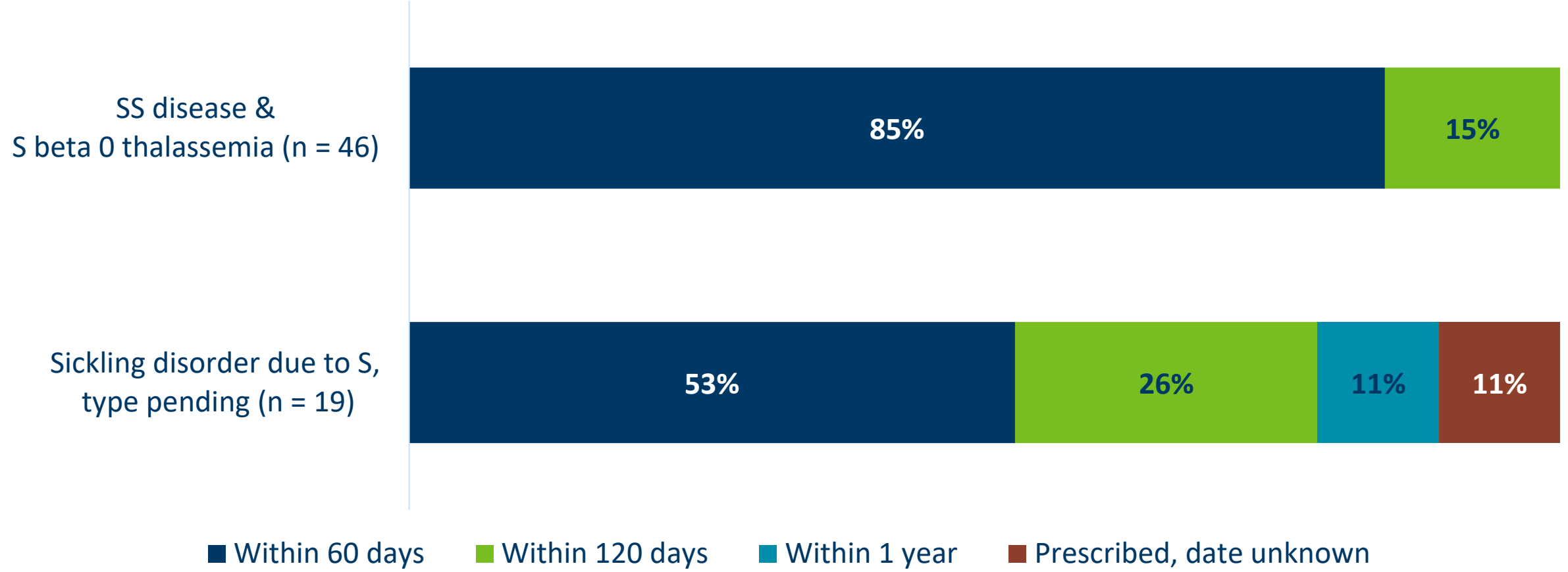
- Mayo Clinic Comprehensive Pediatric Sickle Cell Clinic Department of Pediatrics

**Duluth**

- Essentia Health Duluth Clinic

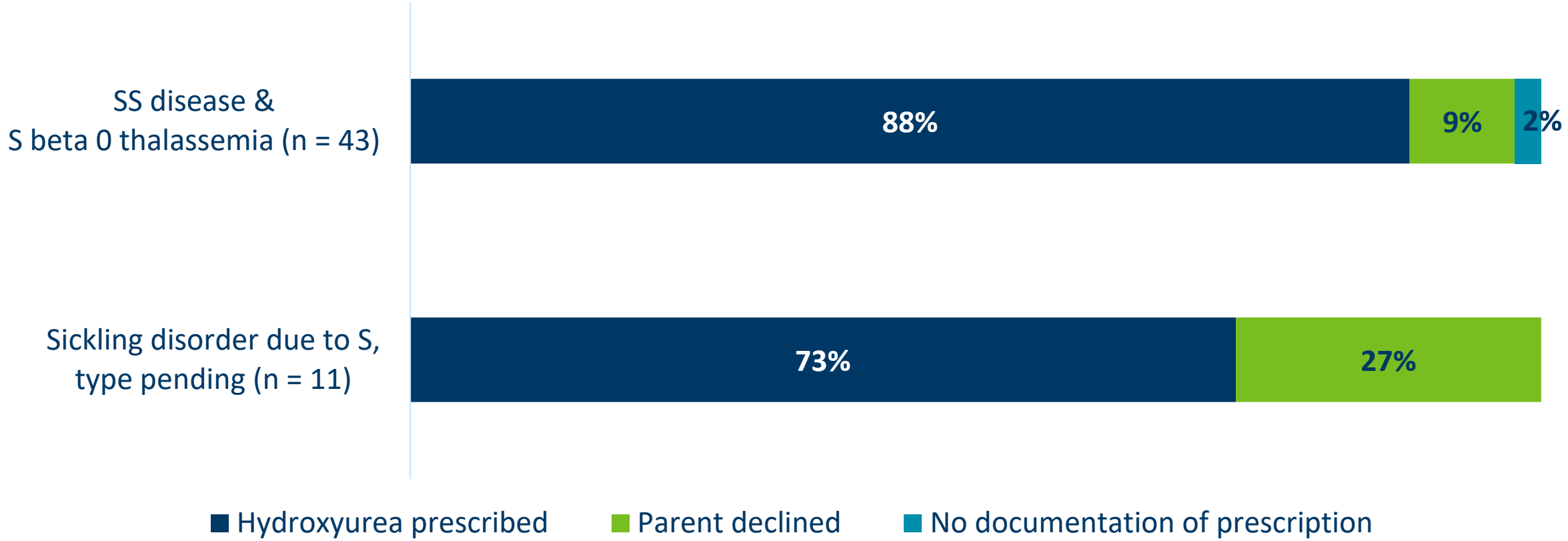
# Penicillin prescriptions by SCD type

*for children identified though Minnesota newborn screening 2018-2024*



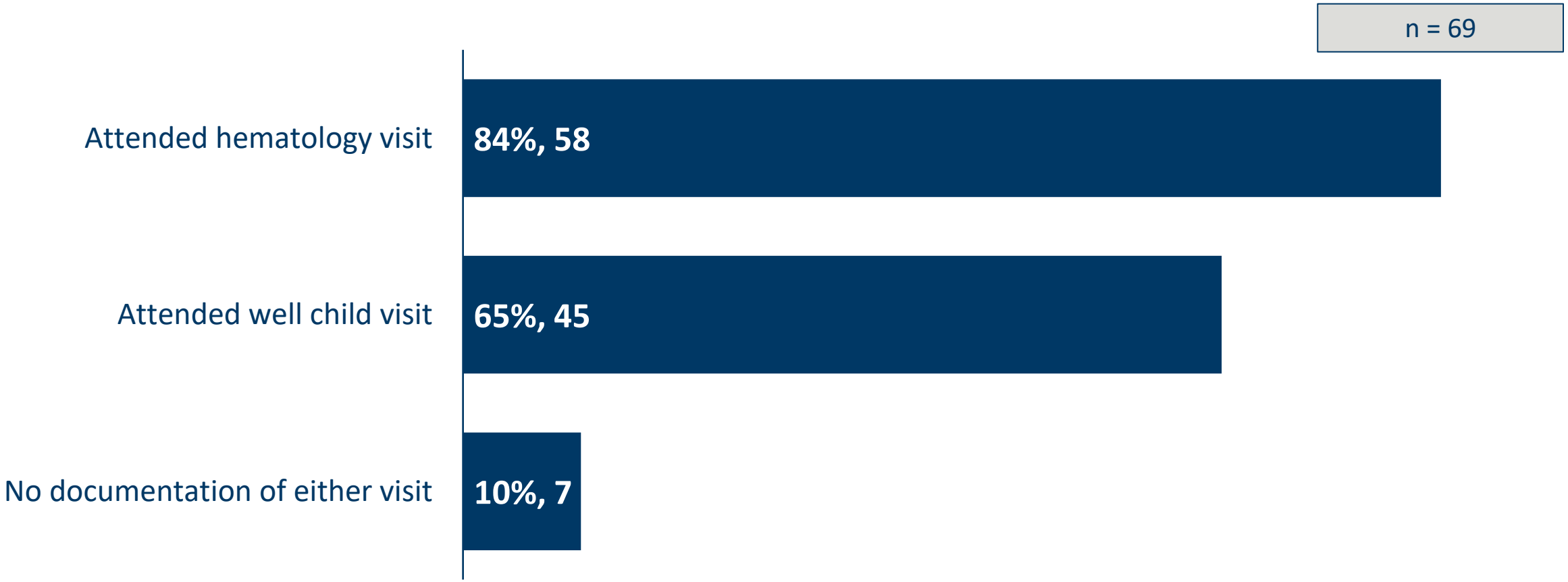

**Based on documentation of a penicillin prescription in a medical chart. This does not necessarily mean that the prescription was filled or that the child is taking the prescription.**

# Hydroxyurea prescribed by SCD type
*in children identified though Minnesota newborn screening 2018-2023*




**Based on documentation of a hydroxyurea prescription in a medical chart. This does not necessarily mean that the prescription was filled or that the child is taking the prescription.**

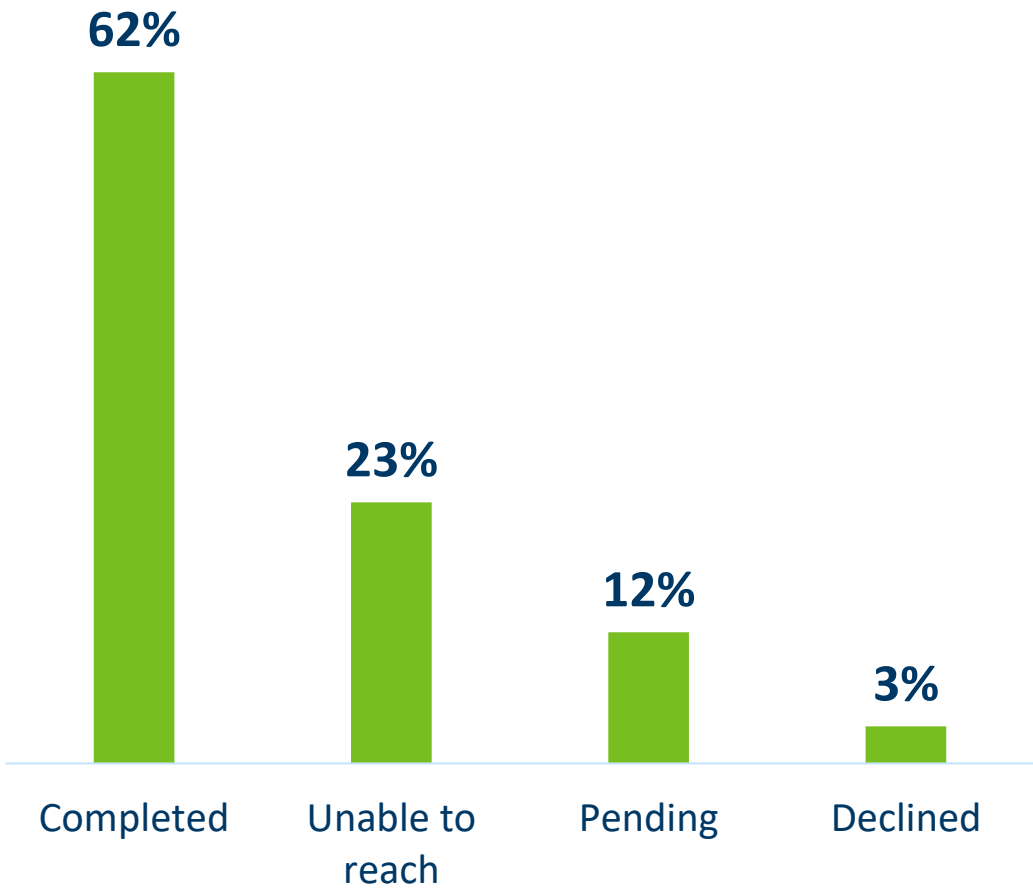
# Hematology or well child visit between 3-4 years of age
*identified though Minnesota newborn screening 2017-2020*



# Local public health assessments

*April 2022 - mid October 2025*

- 60 families referred to LPH for a nursing assessment after their baby was identified with a hemoglobinopathy.
- 62% of those families have received a nursing assessment.



# Now what?

- Educate on the clinical recommendations, when able / appropriate.
  - National Alliance of Sickle Cell Centers (NASCC) (https://sicklecellcenters.org/consensus-recommendations/general)
- Refer to the Sickle Cell Foundation of MN (SCFMN) (www.sicklecellmn.org).
- Sign up to receive our SCD newsletter.
  - September issue (https://content.govdelivery.com/accounts/MNMDH/bulletins/3f0ea22)
- Check out the SCD webpage (www.health.state.mn.us/diseases/sicklecell/index.html).

# Thank you!

www.health.state.mn.us/diseases/sicklecell/index.html

Amanda Maresh
*Amanda.maresh@state.mn.us*

# MN DEPT OF HEALTH

## Local Public Health Nurse Education

November 2025

Presented by:

Rae Blaylark

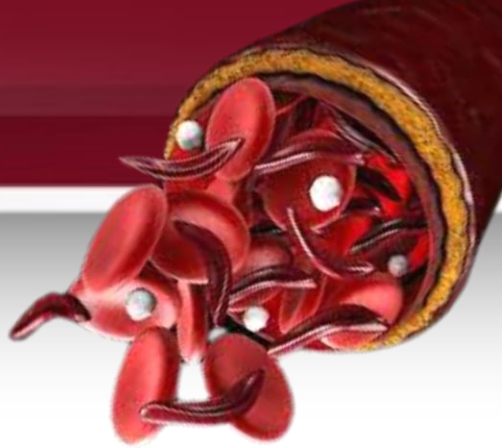
President and Founder

Sickle Cell Foundation of MN

Sickle Cell Foundation

OF MINNESOTA

# Disclosures



- MN Newborn Screening Advisory Council, Council Chair
- MN Rare Disease Advisory Council, Council Member
- HRSA Sickle Treatments and Outcomes Research in the Midwest (STORM), Community Partner
- SCDAA, Member Organization
- Sickle Cell Community Consortium, CBO Member
- Industry Advisory Boards, Consultant

***None of which result in any conflicts of interest pertinent to this presentation***

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# Recognition of Past Trauma and Abuse


It is important that SickleCellMN and those we embrace as allies, both personally and professionally recognize the historical trauma, medical abuse, and discrimination that have impacted our Black, Brown, Indigenous, disability, and LGBTQ+ communities, leading to distrust in medicine.

The work of equity and antiracism requires that we acknowledge the many legacies of violence, displacement, migration, and settlement that bring us together here today and we remain actively committed to being a community bridge, working together to rebuild trust while connecting people, providers, and hope.

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# The Anatomy
# Of A Sickle Cell Warrior


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# Sickle Cell Warriors

**Warrior:** A person engaged in or experienced in warfare; A person engaged in some struggle or conflict.

**Sickle Cell Warrior:** A person who lives with the physical, mental, emotional, and social complications of sickle cell disease, yet faces the journey ahead in spite of unimaginable pain, medical abandonment, stigma & negative messaging, few treatment options, a non-empathetic workforce, repeated death of friends and loved ones, and an uncertain financial future.

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# Caregivers are Warriors Too!

**Warrior Caregivers:**

Those who are charged with providing **Quality of Life** (concrete needs, emotional needs, physical needs, educational needs, financial needs, and advocacy needs) of a person living with sickle cell disease; not withstanding the caregiver's own physical, mental, emotional, and financial needs alongside the repeated challenges and barriers experienced throughout their journey.

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# The DIS-ease of SCD

# Is Sickle Cell Anemia a Black Disease?

- No! It's a BLOOD Disease
- In the U.S. sickle cell disease:
  - Disproportionately, **but not exclusively** affects individuals of African Descent (1 in 365 births per year)
  - Hispanics & Latinx is the 2nd most commonly affected ethnic group is Hispanic Americans (1 in 16,300 births or ~1,200/yr)
- Fact is …

Source: https://www.cdc.gov/ncbddd/sicklecell/index.html

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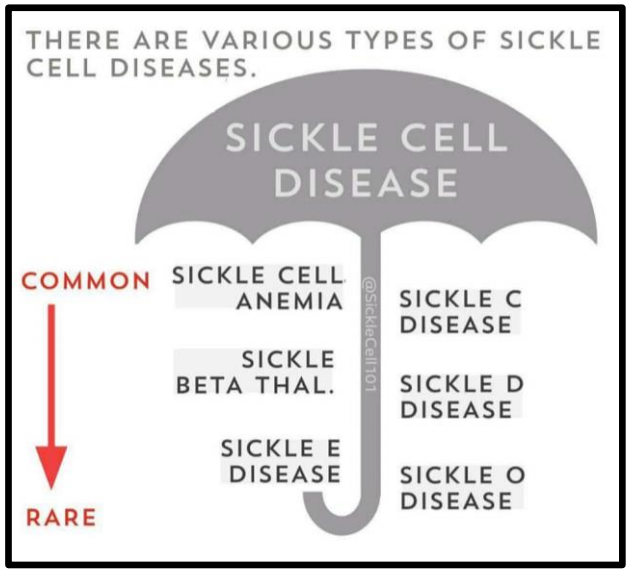
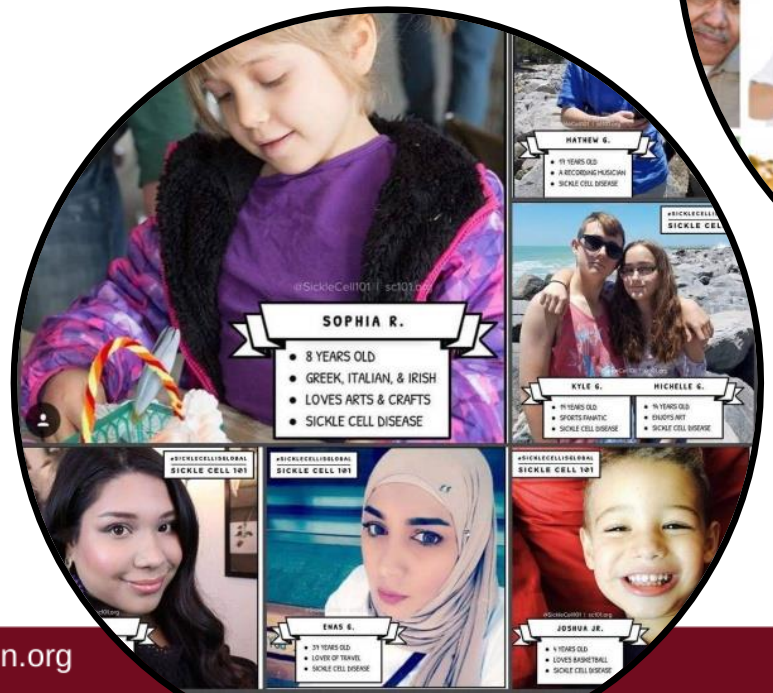
# Sickle Cell DIS-ease:
# The Faces of Sickle Cell

Mutations in the *HBB* gene are most common in people from African, Mediterranean, Middle Eastern, and Indian ancestry as well as people from the Caribbean and parts of Central and South America but can be found in people of **any** ethnicity.

- Hgb variant + Sickle Hgb = **Sickle Cell DISEASE (SCD)**
- Hgb A + Sickle Hgb = **Sickle Cell TRAIT (HbAS)**

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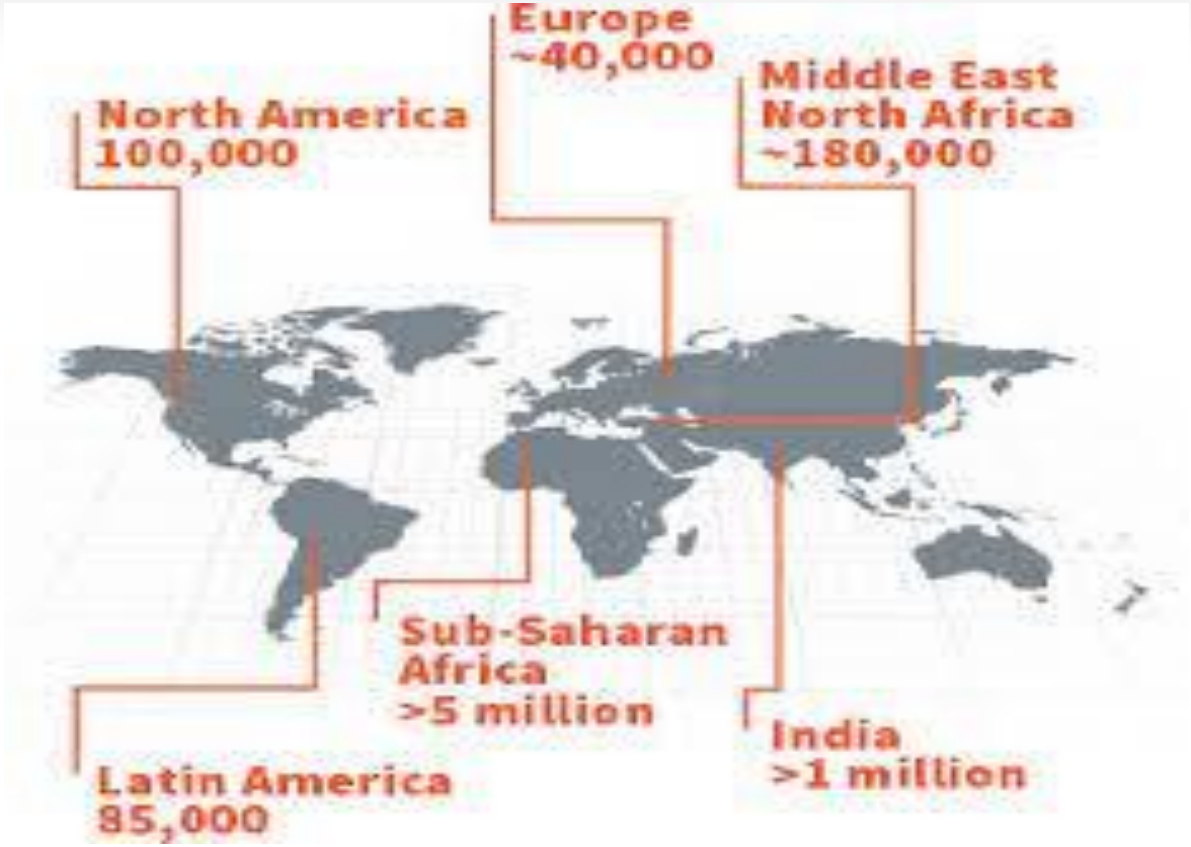
# Sickle Cell DIS-ease: Globally




- Although SCD is the most common genetic blood disorder in the world, **the burden of sickle cell disease is <u>most devastating</u> in Africa.**
- This inequitable burden is directly related to **funding disparities** and the **persistent under resourcing** in relation to the magnitude of the problem.

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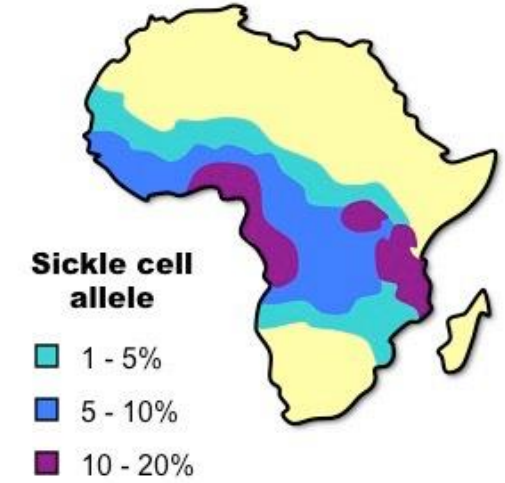
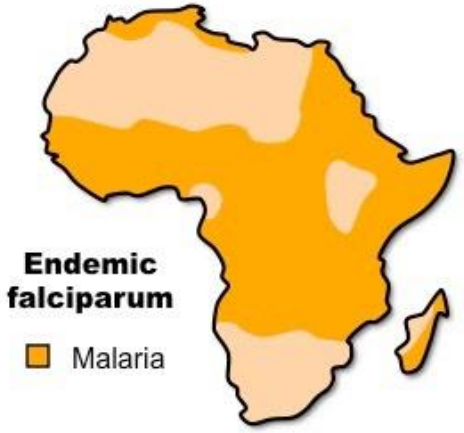
# Sickle Cell and Malaria – The Story of Survival

**Plasmodium falciparum is the type of malaria that most often causes severe and life-threatening malaria**; this parasite is prevalent in many African countries, particularly sub-Saharan Africa (South of the Sahara desert).




Source: https://www.cdc.gov/malaria/about/

Communities that are heavily exposed to the bites of mosquitoes infected with P. falciparum are most at risk of dying from malaria.

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# A Caregiver's Journey

## *Turning Pain into Purpose*

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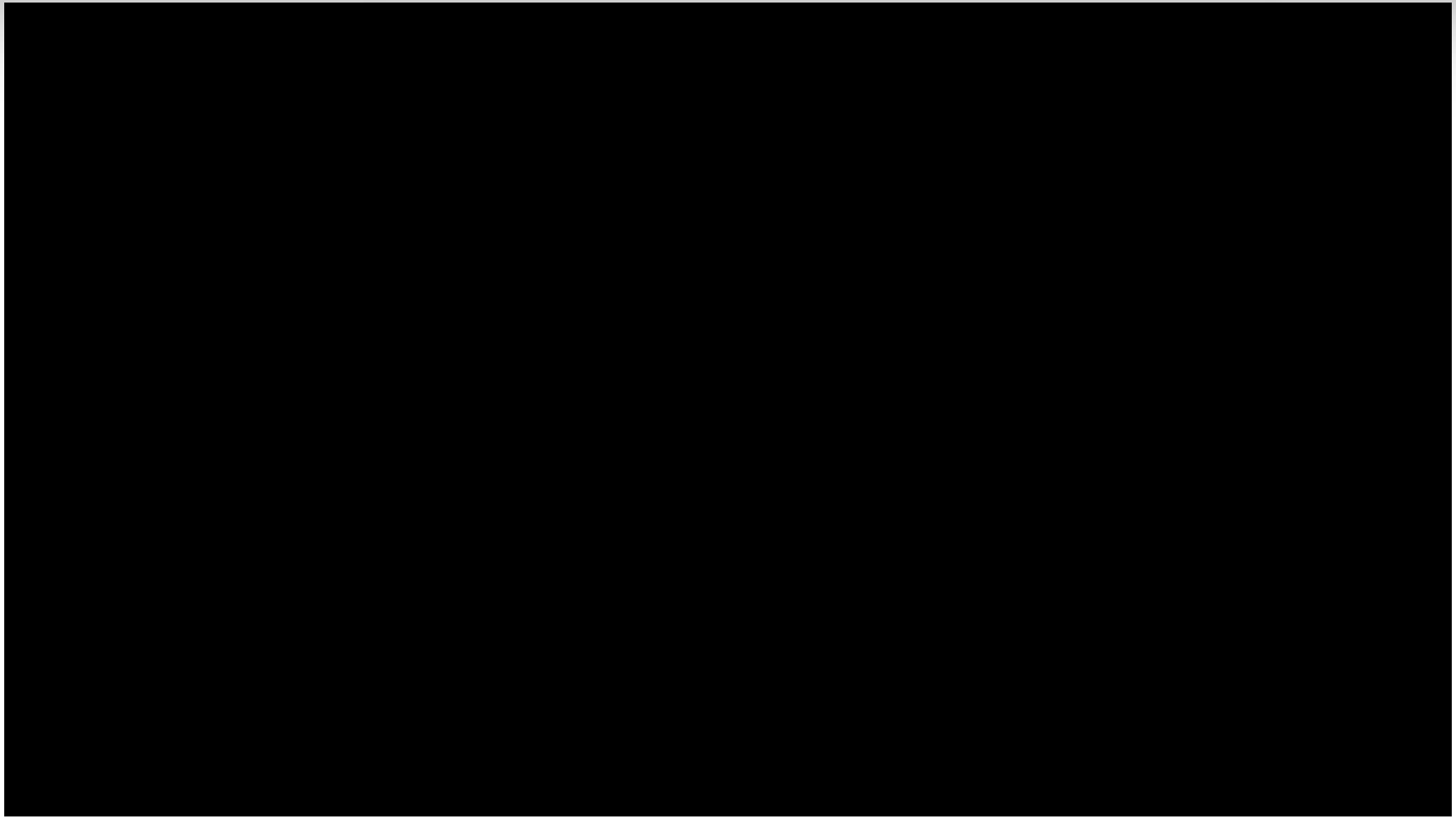
# The Day That Changed Everything…



In the beginning (:52 sec)

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# My Sickle Cell Warrior

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# My Warrior

- Same person
- Different day

# Adjusting Takes Time!

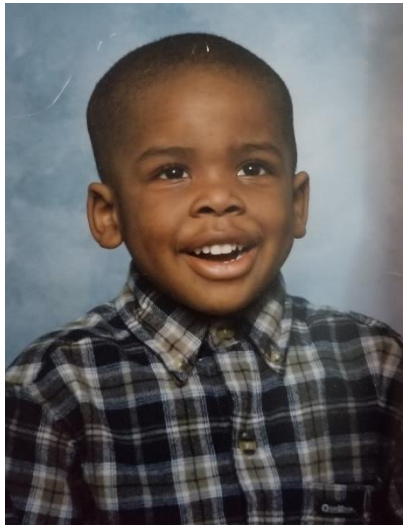
## Learning Objecti

- SCD Diagnosis through MN Newborn Screening

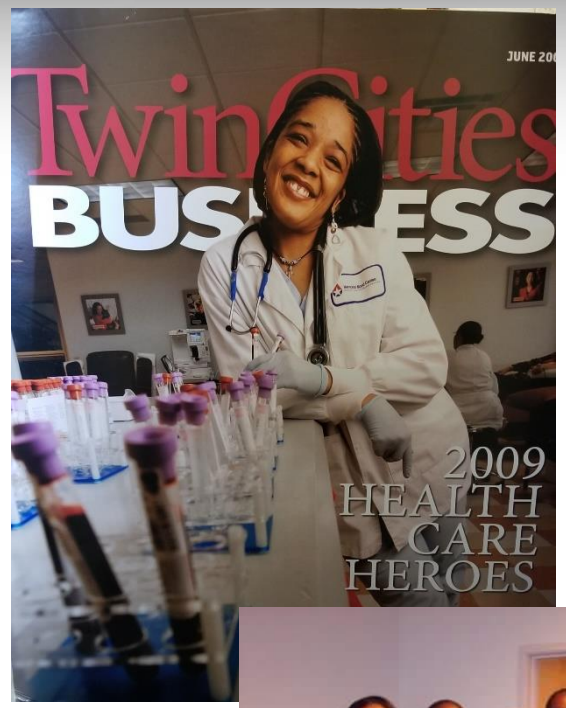
**1997-2003**

**1996**

- Adjusting to our new normal



# Inspired To Do More


- 2004: USPS Releases SCD Postage Stamp
- 2005: Community Awareness: The Journey Begins
- 2005-2014: NEW ROLE: Blood Banking/Donation Advocacy

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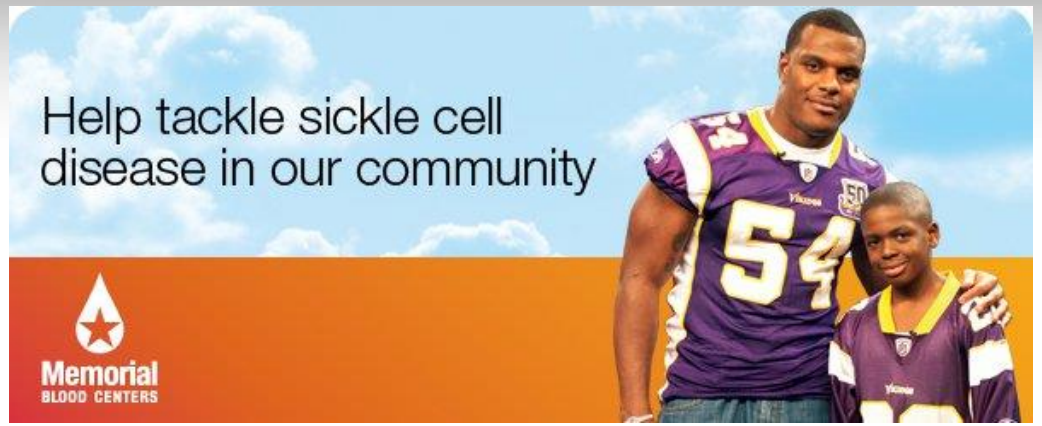
# Using My Pain to Propel My Purpose



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# SCD Care in MN…a glimpse into the reality

SCD Care in MN (1:05)

# Planning For A Future


- Stakeholder Planning Committee
- New Challenge: Son's surgery for congenital spine defect + SCD complications

- SickleCellMN: Online presence only

**2014** — **2015** — **2015–2017**

- New Org: Received 501c3 status for Sickle Cell Foundation of MN (SickleCellMN)
- New Role: Peds SCD Program Coordinator, PT Advocate, DEI Specialist

Sickle Cell Foundation OF MINNESOTA

# Our Early Years…


- **2017** — First Event: Annual Walk 4 Sickle Cell
- **2018** — Walk 4 Sickle Cell; Added: Sickle Cell-ebration of Hope Gala
- **2019** — Added: Statewide Management of Sickle Cell Symposium
- **2020** — Transitioned out of Peds SCD clinic
- **2021/2022** — COVID-19!!!

- **2018** — Walk 4 Sickle Cell; Added: Sickle Cell-ebration of Hope Fundraising Gala

**www.flickr.com/photos/sicklecellmn/albums**

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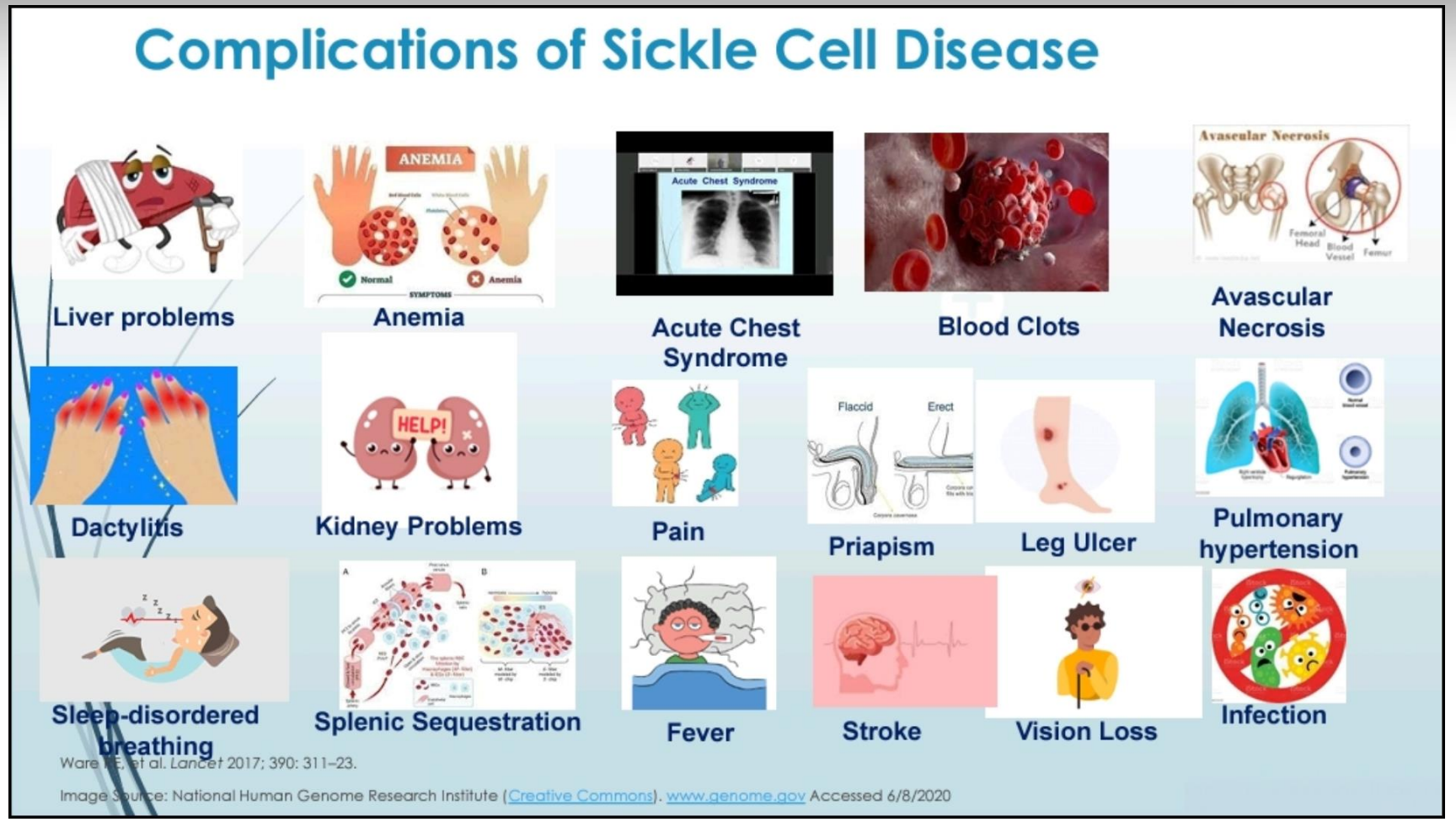
# Caregiver Challenges

## *A Community Afflicted*

# The BIOLOGICAL Impact of SCD



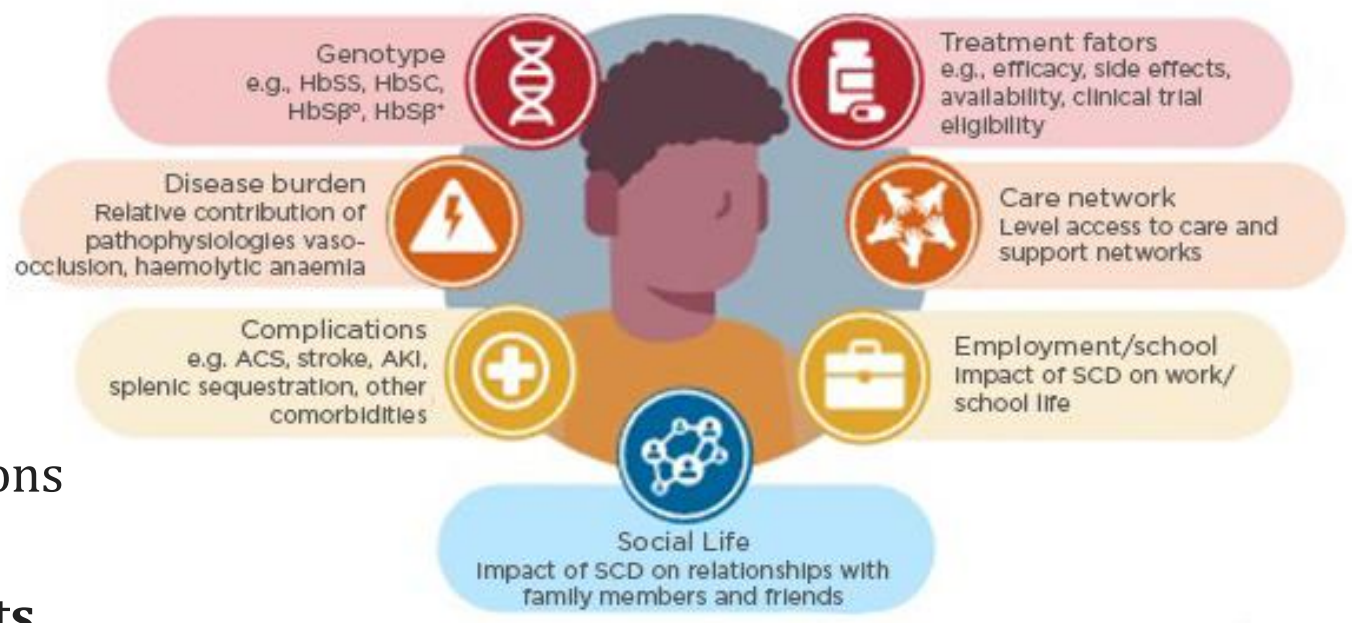

**Blood travels everywhere!**

**This means that complications of SCD occur in EVERY body system**

# The PSYCHOLOGICAL Impact of SCD

As a result of frequent pain, hospitalizations, loss of schooling, employment, and overall quality of life, people impacted by SCD commonly reported **emotional burdens** related to:

- Acute and chronic pain
- Absence from school or work
- Hospitalizations
- Provider bias and insensitivity
- Non-empathetic medical systems
- Missed social interactions
- Missed work opportunities and promotions
- Family Planning
- **Accessing providers and/or treatments**
- **Premature Mortality ---DEATH!!!**




**The psychological consequences of living with a condition like SCD, deeply impacts the entire family's Quality of Life!**

SOURCE: www.ncbi.nlm.nih.gov/pmc/articles/PMC2836308/#:~:text=Mood%20is%20an%20important%20consequence,accounts%20could%20indicate%20depressive%20symptoms

# The SOCIOLOGICAL Impact of SCD

Socio-economic factors often create unfathomable barriers that deeply impact individual or family's ability to consistently prioritize health needs.

- Housing
- Education
- Employment
- Social Support
- Individual/Family Income
- Employment
- Food Security
- Transportation
- Childhood Experiences

**The inability to prioritize one's health needs impacts medical and social burden!**

**Inability does NOT equal a lack of care or concern for oneself**

# Caregiver Burnout

## Mental Health Matters

### Access

Many caregivers face barriers to **culturally competent therapy**, impacting their mental health support.

### Isolation

Isolation occurs in both the caregiver and patient, often as a response to lack of understanding from family, friends, and healthcare professionals.

### Stigma

There's a **persistent stigma** around mental health, leading to reluctance in seeking help within communities.

### Trauma

Collective trauma magnifies the challenges faced, shaping caregivers' experiences and responses to **sickle cell** caregiving.

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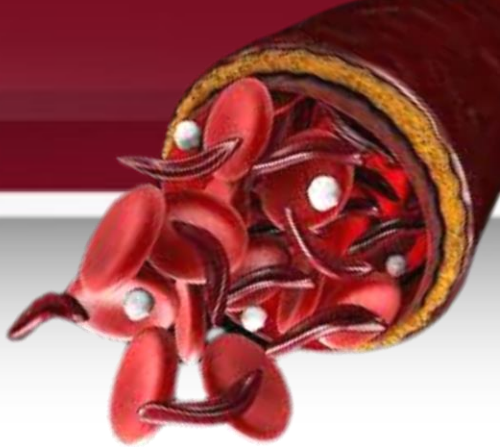
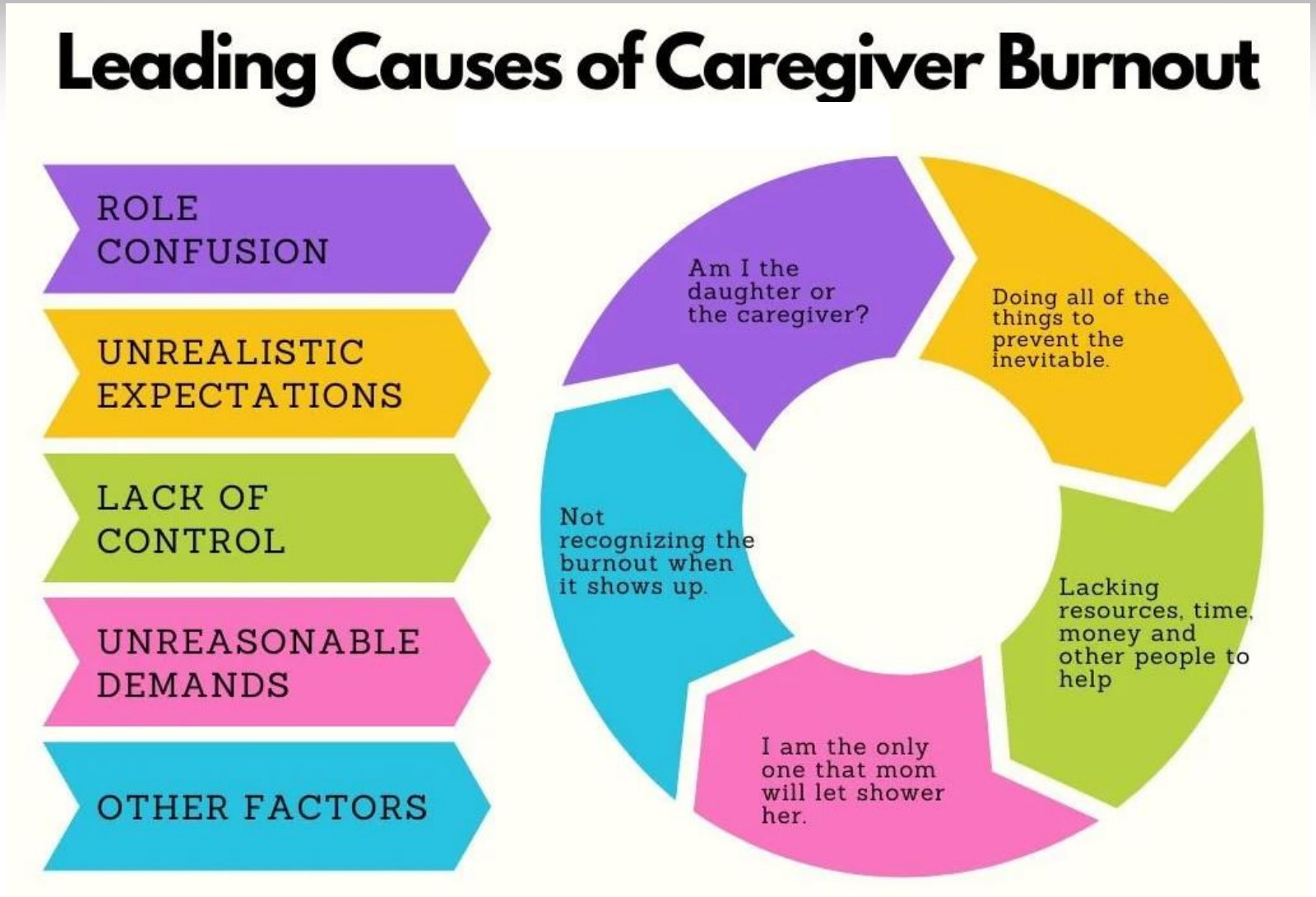
# Caregiver Burnout






Caregiver burnout often occurs faster in homes where other psychosocial burdens are not being met.

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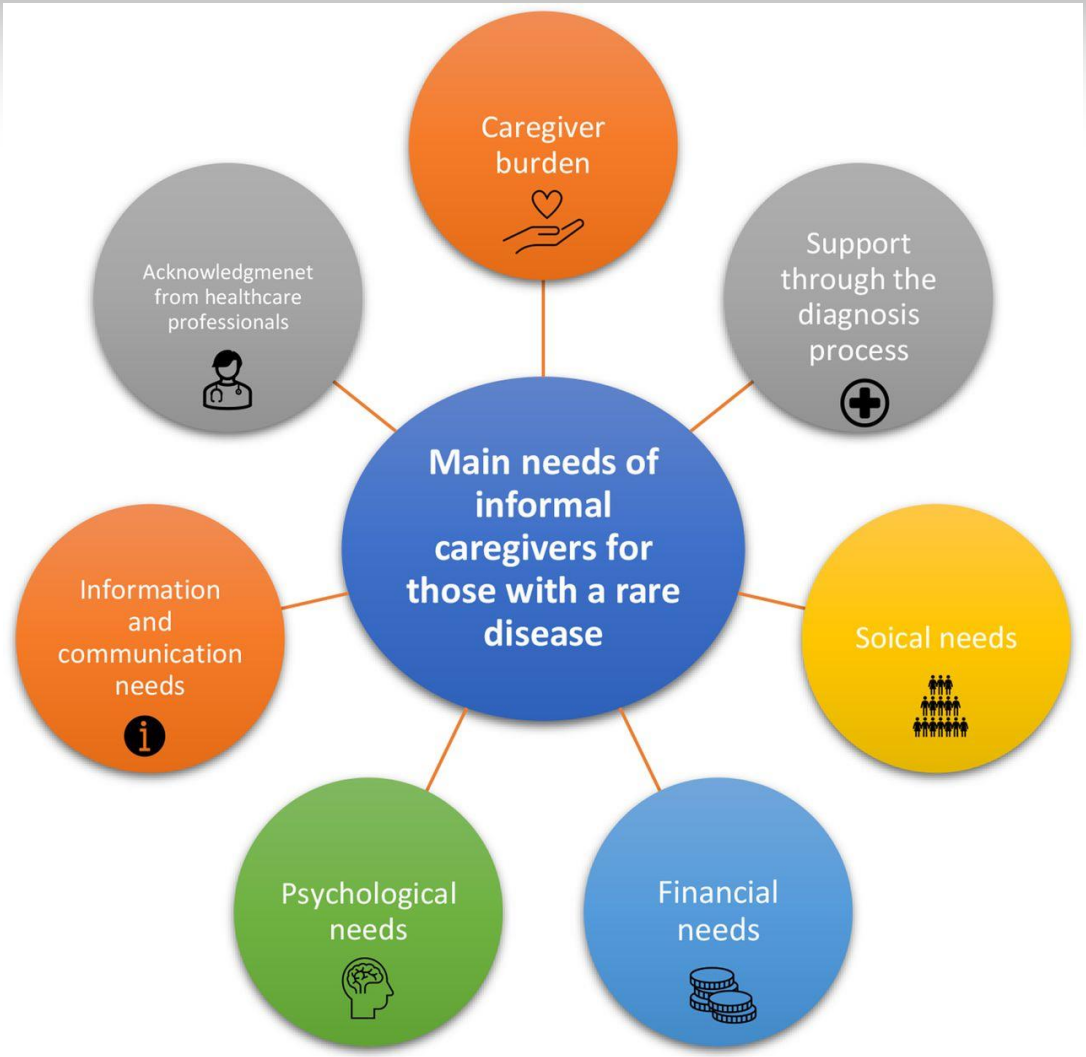
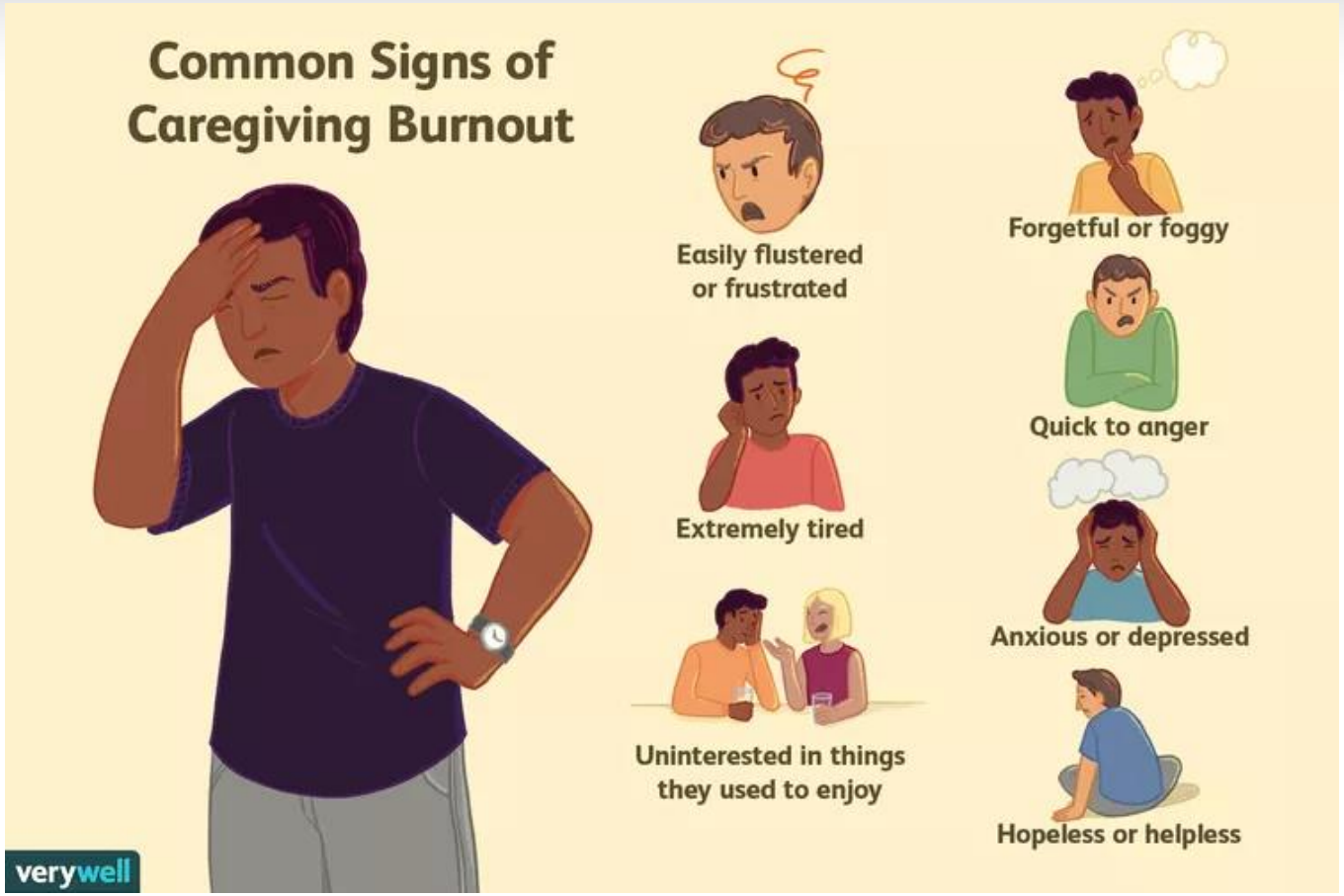
# Supporting Caregiver Mental Health




Caregiver burnout often occurs faster in homes where other psychosocial burdens are not being met.

# Recognize Burnout




Caregiver burnout often occurs faster in homes where other psychosocial burdens are not being met.

# Healing is A Process

## Reconnection

Embracing the beauty of nature helped me rediscover my identity and reconnect with my true self.

## Reflection

Taking time away allowed me to reflect on my journey and understand the lessons learned in caregiving.

## Restoration

Immersing in tranquility facilitated emotional and spiritual restoration, equipping me to return stronger and more resilient.

## Resilience

Recognizing rest as a form of resistance empowered me to prioritize my well-being without guilt or hesitation.

## Purpose

My sabbatical deepened my understanding of my purpose, reinforcing my commitment to advocate for caregivers and warriors alike.

## Growth

Experiencing personal growth during this period illuminated new paths for advocacy and cultural healing in my community.

# Community Healing

In the journey of caregiving, **data and humanity** converge to create significant impact.

Understanding the **psychosocial support** needs of sickle cell warriors and their caregivers is vital. This support nurtures resilience, fostering environments where individuals can thrive.

By combining lived experiences with data, we can **advocate for compassionate policies** that reshape the caregiving landscape and **promote healing within families and communities.**

The strength of the caregiving community lies in **shared experiences and mutual support**.

**Data-informed compassion** can transform lives, guiding effective interventions. Every story told adds depth to the narrative of caregiving, prompting societal change.

**Together,** we can build a collective voice that highlights the importance of our experiences, ensuring that they inform policy decisions and resource allocations that prioritize mental wellness and holistic support.

# History of Sickle Cell DIS-ease

# SCD: A Rare Blood Disorder

**1 in 10**

People are Affected by Rare Disease

**1 in 2**

Rare Diseases Don't Have a Foundation or Research Support Groups

**1 of 2**

Patients Diagnosed with a Rare Disease is a Child

**400**

Million People Suffer From a Rare Disease Globally

**8 in 10**

Rare Diseases are Genetic

**6+ Years**

The Average Time it Takes for Rare Patients to Receive an Accurate Diagnosis *https://everylifefoundation.org/delayed-diagnosis-study/*

**95%**

of Rare Diseases Lack an FDA Approved Treatment

**10,000+**

Distinct types of Rare and Genetic Diseases

**Up to $517,000**

*The economic impact of a delayed diagnosis is up to $517,000 in avoidable costs per patient.*

globalgenes.org/ raregiseases.info.nih.gov/diseases/pages/31/faqs-about-rare-diseases https://rarediseases.info.nih.gov

Sickle Cell Foundation of Minnesota

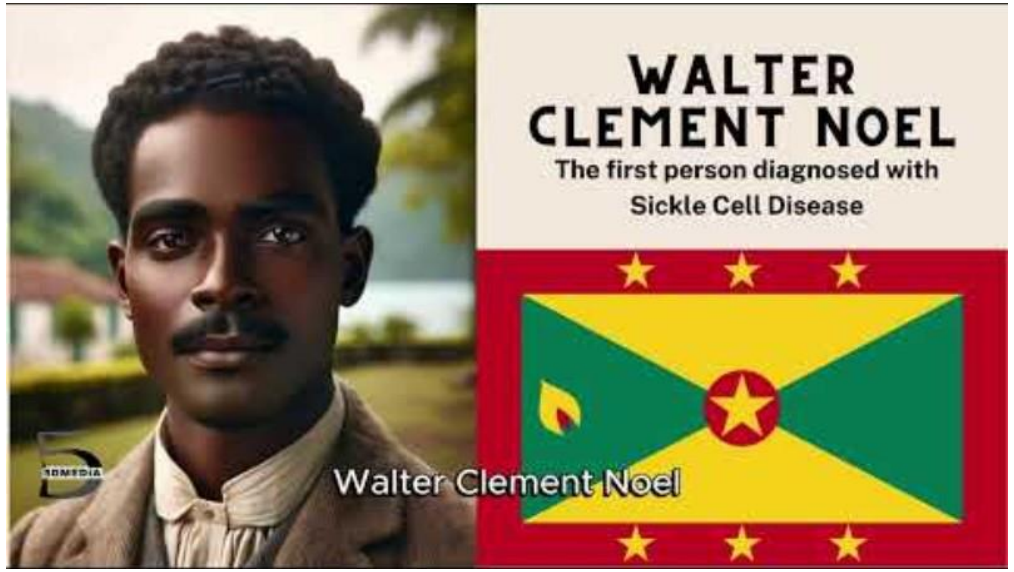
# History of Sickle Cell Disease

## Walter C. Noel (1884-1916)

### A Legacy of Enduring Importance

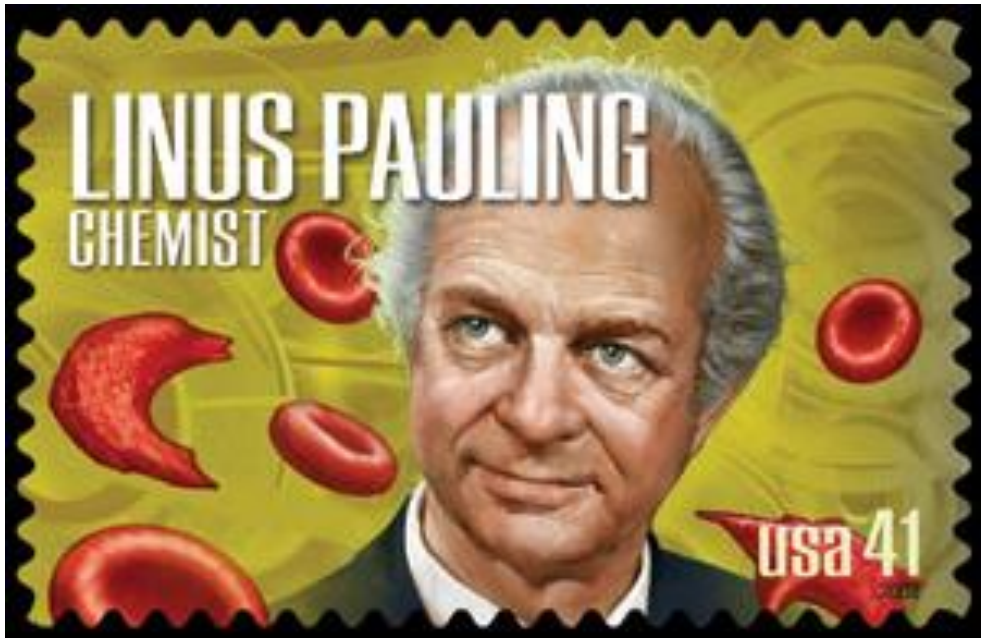
***From a Dental Student to a Medical Hero***

- Only African student ever enrolled at **Chicago College of Dentistry** in 1904
- Suffered many leg ulcers (treated w/iodine)
- Admitted with (now known as) Acute Chest Syndrome (ACS) only 3 months after arriving in U.S.
- Returned to Grenada in 1907 after graduating dental surgeon school
- First SCD case presented to AAP and clinically described in the Archives of Internal Medicine (1910, USA)
- Established a successful dental practice
- Died of ACS in 1916 at 32 yo




Source: www.mayoclinicproceedings.org/article/S0025-6196(11)60243-7/fulltext

# History of Sickle Cell Disease




- Presented first case to AAP and clinically described in the Archives of Internal Medicine (1910, USA)
- 1927 – Discovered that red blood cells (RBC's) from persons with SCD could be made to sickle by removing oxygen
- 1951 – SCD was the first to be labeled a "molecular disease" after discovering that the red, oxygen carrying protein called "hemoglobin" had a different chemical structure in persons with SCD

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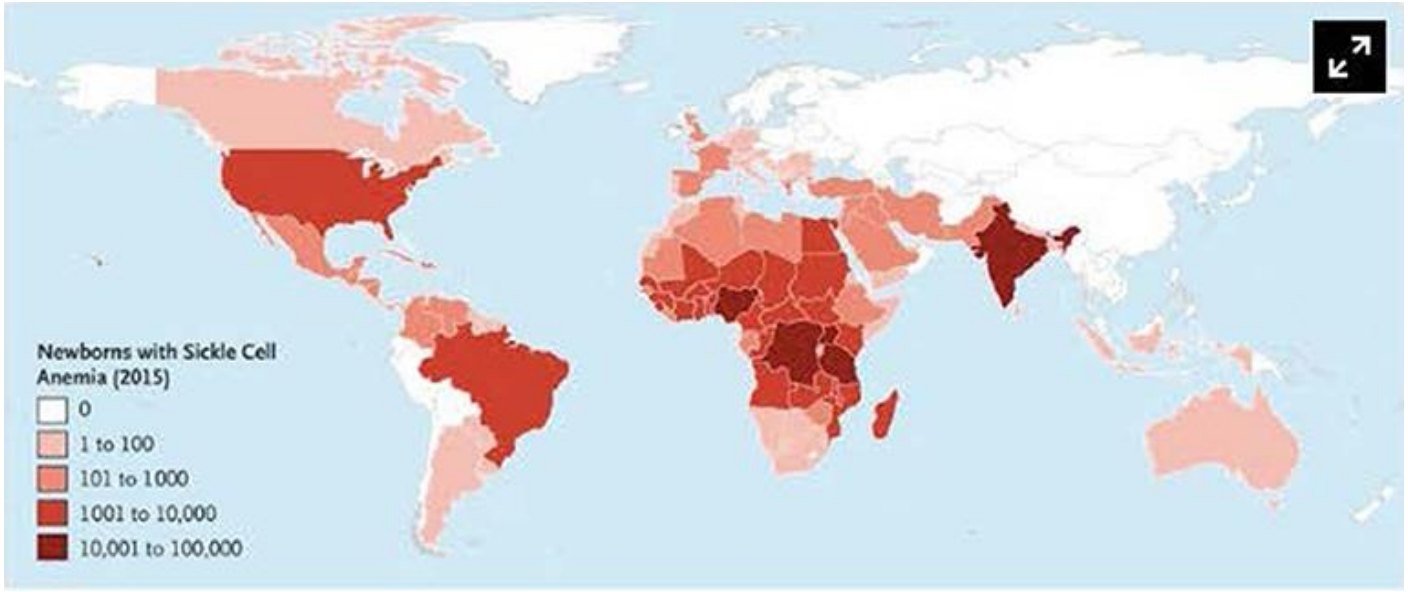
# The GLOBAL Impact of SCD

Between 2000 and 2021 births of babies with sickle cell disease **increased globally by 13·7%**.




Globally, the number of people **living** with sickle cell disease **increased by 41·4%,** from **5.46M** in 2000 to **7.74M** in 2021.

SOURCE: www.healthdata.org/research-analysis/library/global-regional-and-national-prevalence-and-mortality-burden-sickle-cell#:~:text=We%20estimated%2034%20400%20(25,303%20000%E2%80%93467%20000)

Sickle Cell Foundation OF MINNESOTA

# Global Geographic Concentration


Six countries make up **44% of global cases**.
Nigeria • Benin • Burkina Faso • Togo
Sierra Leone • Equatorial Guinea

**Sub-Saharan Africa** accounts for nearly **80% of global births** with SCD

**India** remains a major contributor, but their global share of the burden declined 21% in 2000 to 16% in 2021.

SOURCE: www.healthdata.org/research-analysis/library/global-regional-and-national-prevalence-and-mortality-burden-sickle-cell#:~:text=We%20estimated%2034%20400%20(25,303%20000%E2%80%93467%20000)

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# The MORTALITY of SCD

**In children younger than 5 yo, global SCD mortality ranks 12th (compared to 40th for cause-specific SCD mortality) across all causes.**

SOURCE: www.healthdata.org/research-analysis/library/global-regional-and-national-prevalence-and-mortality-burden-sickle-cell#:~:text=We%20estimated%2034%20400%20(25,303%20000%E2%80%93467%20000)

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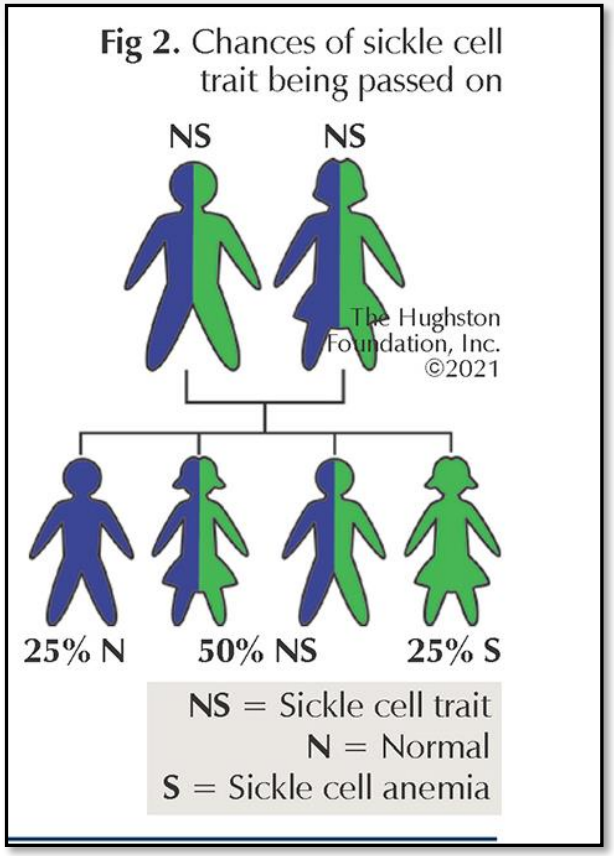
# Sickle Cell Trait: Nationally




As many as 60,000 children in the United States were born with the **sickle cell trait** annually.

| | |
|---|---|
| ~73 per 1,000 | BLACK INFANTS |
| ~7 per 1,000 | HISPANIC INFANTS |
| ~3 per 1,000 | WHITE INFANTS |
| ~2 per 1,000 | ASIAN, NATIVE HAWAIIAN, OR OTHER PACIFIC ISLANDER INFANTS |

*Data reported in 2010, based on newborn screening information provided by 13 states.

Source: www.cdc.gov

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# Sickle Cell Disease: Nationally

Centers for Disease Control and Prevention (CDC) estimates that **sickle cell impacts ~100,000 Americans** (per 2010 study published in AJPM)


| | |
|---|---|
| ~1 of 365 | BLACK INFANTS |
| ~1 of 16,300 | HISPANIC INFANTS |
| ~1 of 25,800 | ASIAN, NATIVE HAWAIIAN, OR OTHER PACIFIC ISLANDER INFANTS |
| ~1 of 41,600 | WHITE INFANTS |

*Based on births in New York State between 2000 and 2008.

New estimates for the prevalence of sickle cell disease in the United States will rely heavily on *consistent and complete reporting* data by **universal newborn screening information**

**New CDC data coming soon???**

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# Population & Market Growth

## As cases rise so do the number of treatments and therapies in the pipeline!

**Population growth:** As the global population expands, particularly in regions where SCD is more common, the number of cases naturally increases.

**Migration:** Migration of populations from affected areas to developed countries contributes to the global increase in SCD cases.

**Improved Diagnosis:** Better diagnostic tools and increased awareness lead to more accurate and earlier identification of the disease.

**Market growth trends**

- While not a direct measure of disease prevalence, the market size for SCD treatments is expected to grow substantially.
- The market is projected to reach USD 16.01 billion by 2035, with a compound annual growth rate (CAGR) of 16.0%.
- This market growth reflects advancements in treatments and increased investment in the field.

**Sickle Cell Disease remains an invisible global health problem**
**That is expected to increase by 40% over the next**

Source: www.bmj.com/content/347/bmj.f4676.full#:~:text=1Kolkata,sickle%20cell%20anaemia%2C%20it%20estimates

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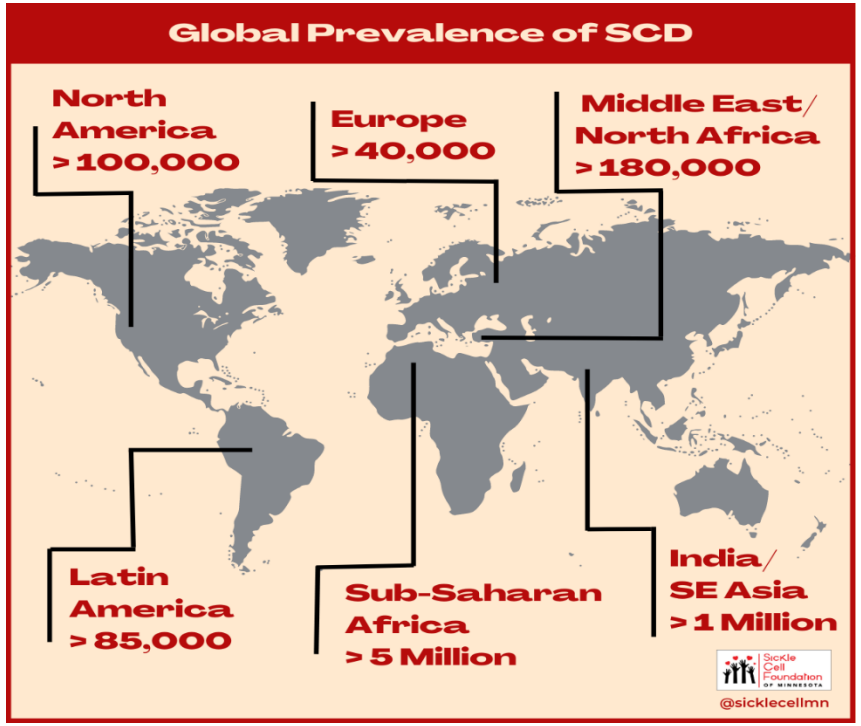
# The GLOBAL Impact of SCD

## Sickle Cell Disease (SCD) is NOT a Black disease, IT'S A BLOOD DISEASE!




**SCD is the most common genetic blood disorder in the world!**

Global Prevalence Estimations:

- **~ 7,000,000+** people with SCD
- **~ 400,000+** born w/SCD each year with SCD
- **~300,000,000** people have SC Trait (and can pass SCD to their children)

**5% of the world's population carries SC Trait!**

SOURCE: www.healthdata.org/research-analysis/library/global-regional-and-national-prevalence-and-mortality-burden-sickle-cell#:~:text=We%20estimated%2034%20400%20(25,303%20000%E2%80%93467%20000)

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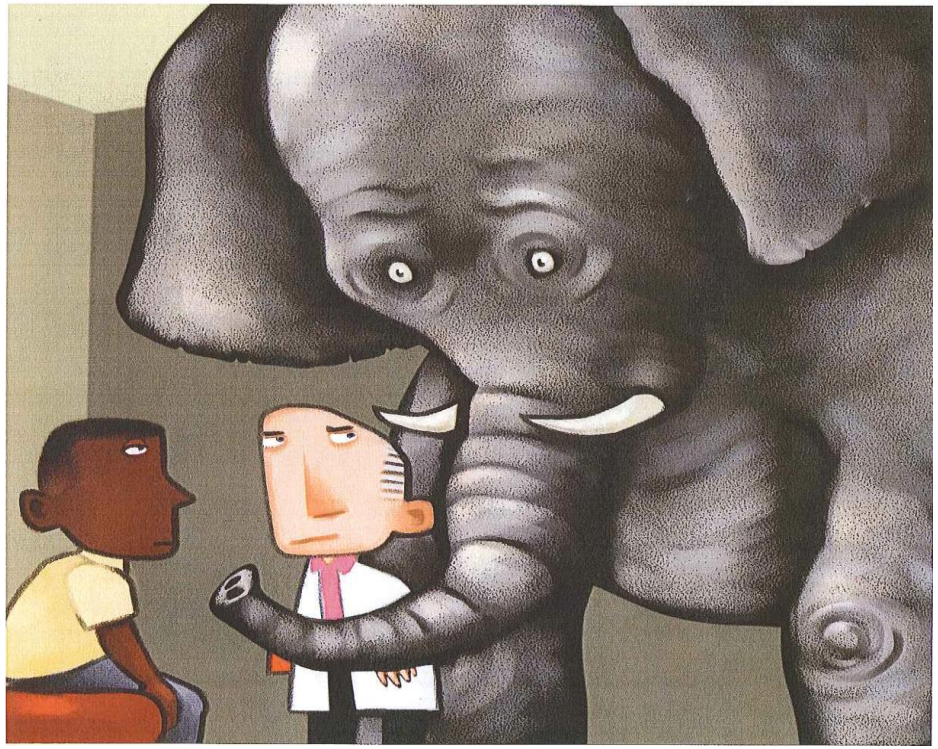
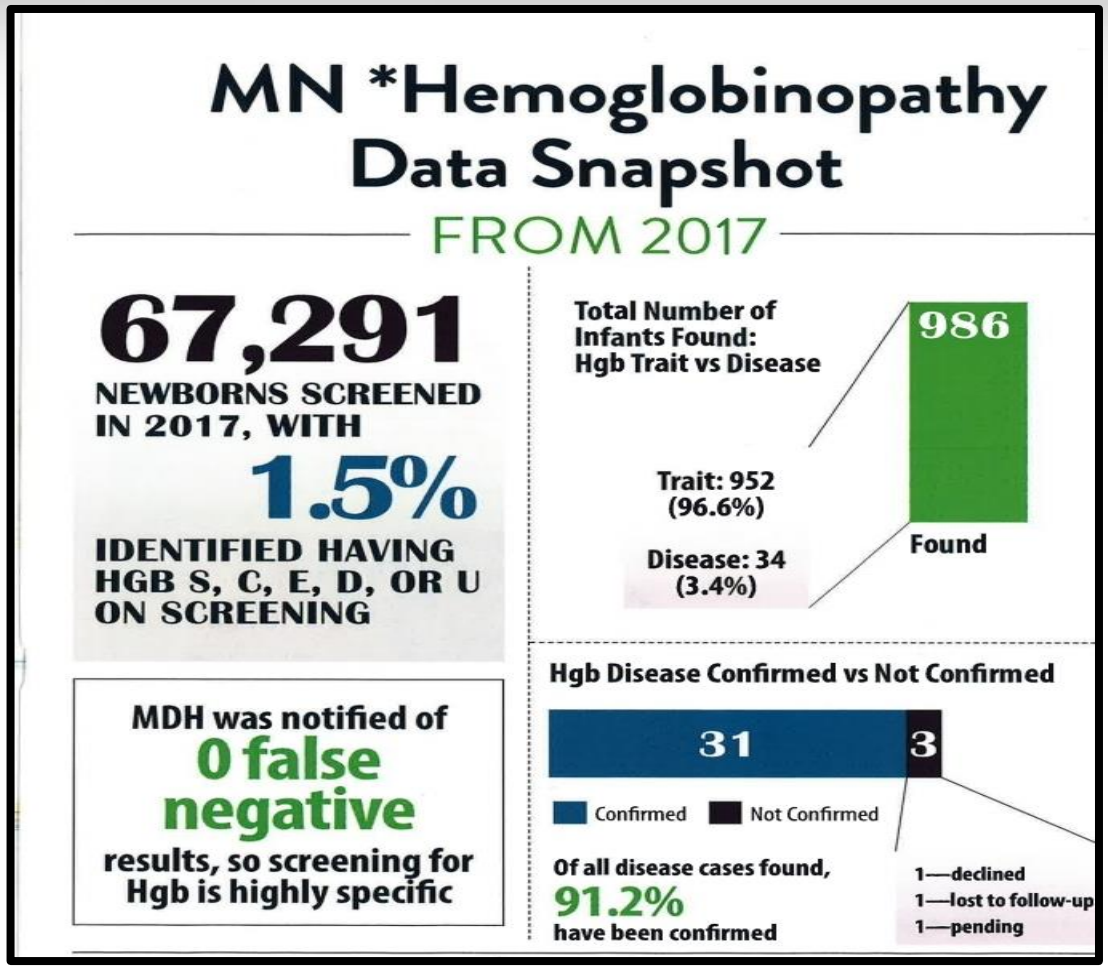
# The Elephant in the Room: Systemic Inequalities



# The Day That Changed Everything… (cont.)


In the beginning (:52 sec)

# Sickle Cell DIS-ease: Locally




## Sickle Cell DIS-ease: a local perspective

- 1910: First described in Western medical literature in Dr. James Herrick, who was treating a dental patient from the Caribbean island of Grenada.
- The first formal description in Western medical literature was in 1910 by Dr. James Herrick, who observed the sickle-shaped red blood cells in a patient named Walter Clement Noel.
- 1972 Sickle Cell Anemia Control Act (Nixon)
- 1988: Sickle Cell Disease is added to Newborn Screening (NBS)
- 2015: Trait Notification Program added to NBS
- 30+ years of being under-educated leaves a community mis-educated

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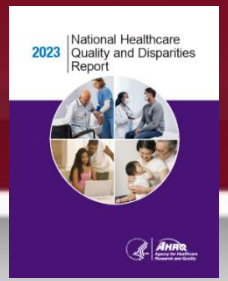
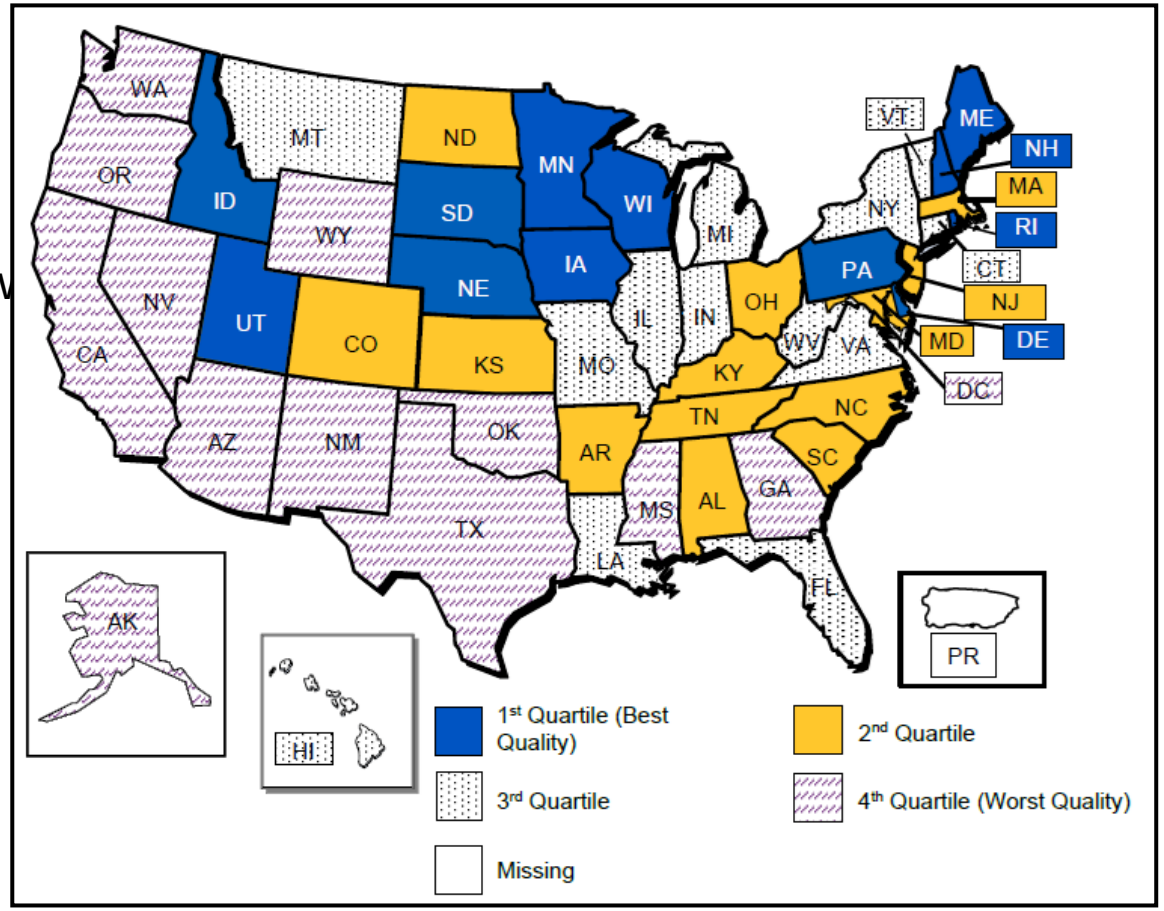
# 2023: National Health Quality and Disparities Report

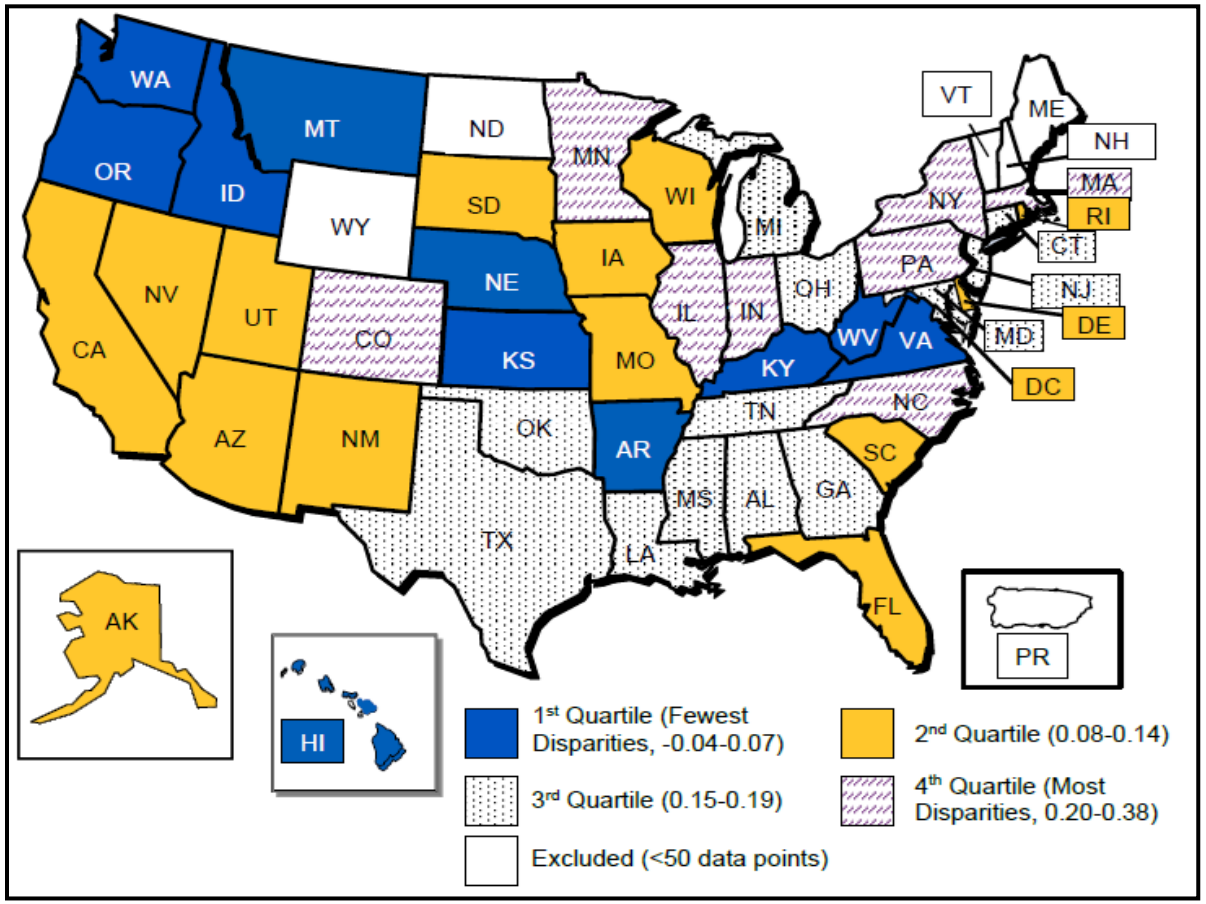



## Overall Quality of Care by State (2016-2021)

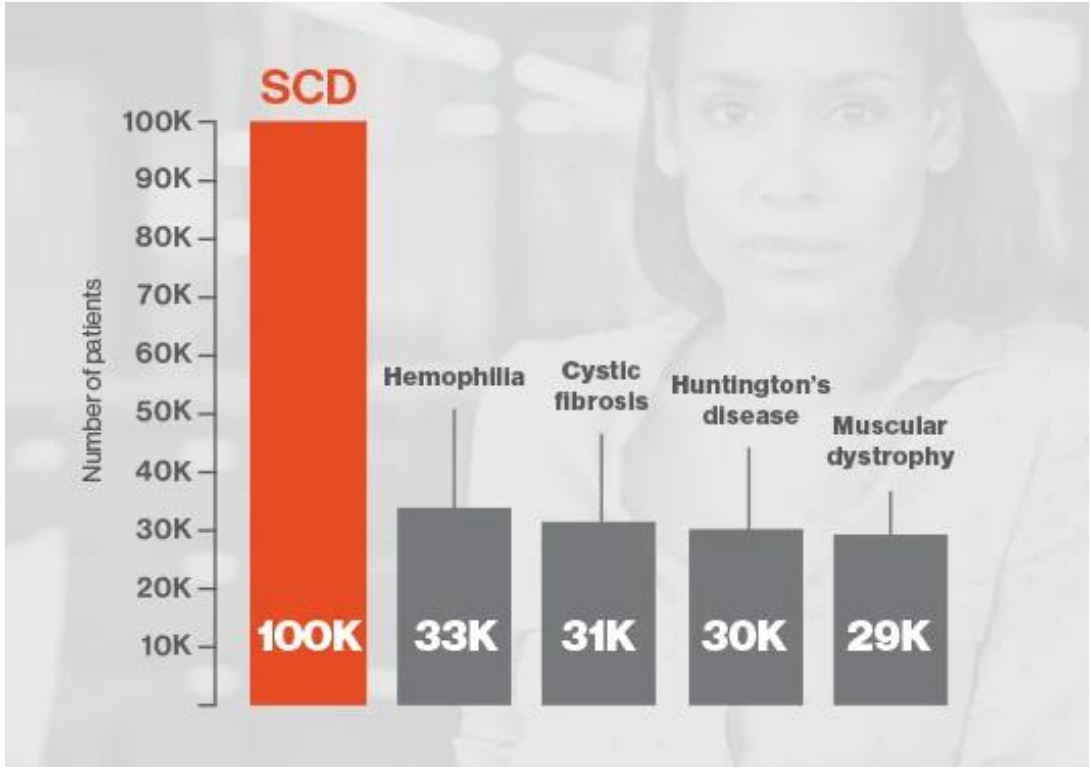



## Average differences in quality of care (2016-2021)

**For American Indian or Alaska Native, Asian, Black, Hispanic, Native Hawaiian/Pacific Islander, and multiracial people compared with non-Hispanic White or White people, by state**



# Systemic Inequities and Medical Bias




## Racialized Disease Classification

- In the U.S., SCD primarily affects Black & Brown communities
  - Over 90% of U.S. cases are in Black or African American children (1 in 365 AA births)
  - Most new, non-U.S. born, patients are of African descent
  - Hispanic communities are second most common (1 in 16,300
- Funding disparities and underprioritized compared to diseases like cystic fibrosis, which affects dominant populations.
  - SCD was identifies in 1910 and has only 3 FDA approved DMTs

## Access Barriers

- Inconsistent access to hematologists and comprehensive care centers, particularly in rural and low-income urban areas.
- Fewer pediatric SCD specialists across the Midwest and Southern states despite higher disease prevalence.
- Insurance type often determines access—not medical need.

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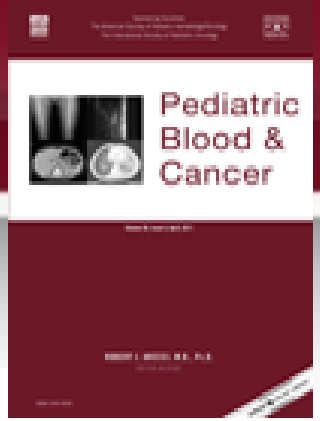
# Systemic Inequities in Sickle Cell Care

- **Racialized Disease Classification**
  - In the U.S., SCD primarily affects Black & Brown communities
    - over 90% of U.S. cases are in Black or African American children (1 in 365 AA births)
    - Most new, non-U.S. born, patients are of African descent
    - Hispanic communities are second most common (1 in 16,300
  - SCD was identifies in 1910 and has only 3 FDA approved DMTs
    - Funding disparities and underprioritized compared to diseases like cystic fibrosis, which affects dominant populations.
- **Pain Management Disparities**
  - Black children with SCD in emergency rooms **wait longer for pain medication**, receive **less potent analgesics**, and are **less likely to be believed** about their pain.
  - A 2013 study showed children with SCD waited nearly **50% longer** for pain relief compared to white children with similar conditions (e.g., long-bone fractures).
- **Access Barriers**
  - Inconsistent access to hematologists and comprehensive care centers, particularly in rural and low-income urban areas.
  - Fewer pediatric SCD specialists across the Midwest and Southern states despite higher disease prevalence.
  - Insurance type often determines access—not medical need.




Pediatr Blood Cancer 2013;60:451–454

# Race Matters: Perceptions of Race and Racism in a Sickle Cell Center

Stephen C. Nelson, MD[1]* and Heather W. Hackman, EdD[2]

***Background.*** Health care disparities based on race have been reported in the management of many diseases. Our goal was to identify perceptions of race and racism among both staff and patients/families with particular attention to provider attitudes as a potential contributor to racial healthcare disparities. ***Procedure.*** A confidential survey addressing issues of race and health care was given to all patients with sickle cell disease and their families upon arrival to clinic. The survey was made available online to all staff in the hematology/oncology program. Free text comments were obtained. ***Results.*** We received completed surveys from 112 patients/families. Surveys were completed by 135 of 158 staff members (85% return rate). The majority (92.6%) of patients/families identified as black, while 94.1% of staff identified as white ($P < 0.001$). More patients/families felt that race affects the quality of health care for sickle cell patients (50% vs. 31.6%, $P = 0.003$). More staff perceived unequal treatment of patients, especially in the inpatient setting (20.9% vs. 10.9%, $P = 0.03$). ***Conclusions.*** Provider attitudes contribute to continued racial health care disparities. We propose training health care providers on issues of race and racism. Training should provide critical thinking tools for improving medical providers' comfort and skills in caring for patients who are of a different race than their own. Pediatr Blood Cancer 2013;60:451–454. 

**Key words:** health care disparity; race; sickle cell disease

# Believe Our Pain

www.scdbelieveit.org (@formatherapeutics) :30

# Community-Based Organizations (CBO's)

# Community Based Organizations

A Community-Based Organization (CBO) **provides key supportive services to the community or targeted population within the community**

**Many CBOs include all or some of the following services:**

- Direct Services (case management, testing, etc.)
- Support Services (financial and concrete needs)
- Advocacy Services (navigator, liaison, etc.)

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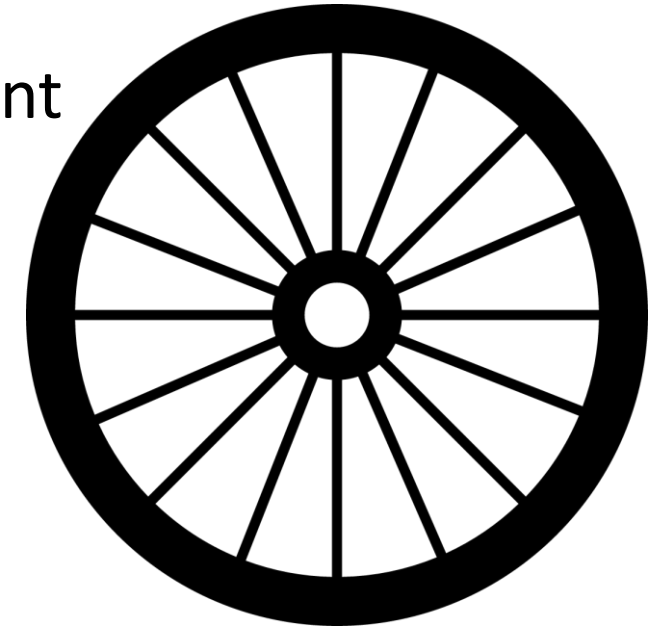
# Community Development and Capacity Building

- The CBO serves as another spoke in the wheel of **community development** and it's infrastructure and should be well grounded in:

Sense of Belonging

Self-Empowerment

Social Justice



Human Rights

Self Determination

Soft Skill Development

Collective Action

**SOURCE:** https://aifs.gov.au/resources/practice-guides/what-community-development#:~:text=Community%20development%20is%20a%20holistic,action%20(Kenny%2C%202007)

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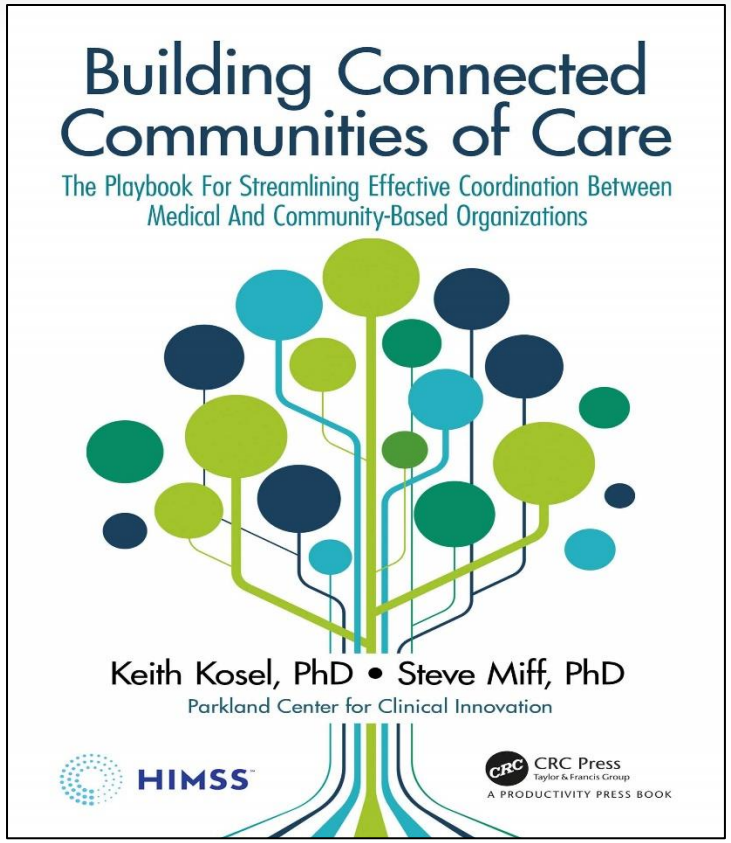


## Community-Based Organizations (CBO's)

Community-based direct services & supports:

- Community Health Workers
- Community Education
- Support Groups
- Community activities & events
- Advocacy/leadership training
- Other patient support (concrete needs, transportation, financial assistance, etc.)

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# CARING PROVIDERS vs. INEQUITABLE SYSTEMS

## Can you relate?

**You!**

**The perceived response from your department or hospital!**

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# THE ROLE OF CBO's

**How we're often utilized with partners**

**How we're best utilized with partners!**

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# ORG OVERVIEW

# WHO WE ARE AND WHAT WE DO

Sickle Cell Foundation OF MINNESOTA

## Mission:

Improving quality and quantity of life of life for individuals and communities affected by sickle cell disease and sickle cell trait.

## Vision:

To educate all communities and connect affected individuals to one another, to expert medical care, and to meaningful resources, all of which assist individuals in achieving better health while living up to their fullest potential.

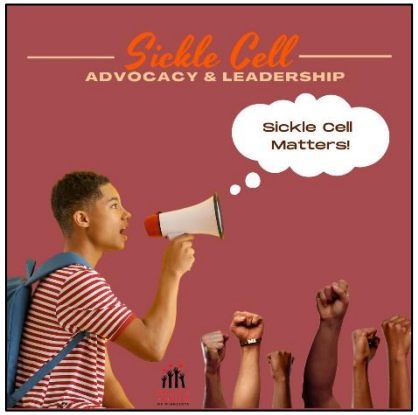
## Values:

Our commitment to the sickle cell community is deeply rooted in our belief that we are stronger together than as one. We value our individual and community health, equitable access to compassionate expert care and community-centered solutions. Through collaborative relationships, we create partnerships that increase meaningful and healthy interactions with one another and with the healthcare community.

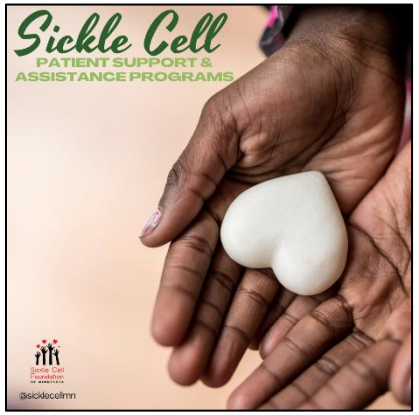
# Program Overview

**Outreach Programs**

- Sickle Smart Education Programs
- Advocacy & Leadership Programs
- Community Wellness Programs
- Patient Support & Empowerment Programs

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# Community Engagement (and the Use of Social Media)


www.sicklecellmn.org


www.linktr.ee/sicklecellmn

# Community Engagement (and the Use of Social Media)

## 10,000+ followers on Social Media!!!


3K+ Followers


~3K+ Followers


2K Followers


700+ Followers


800+ Followers

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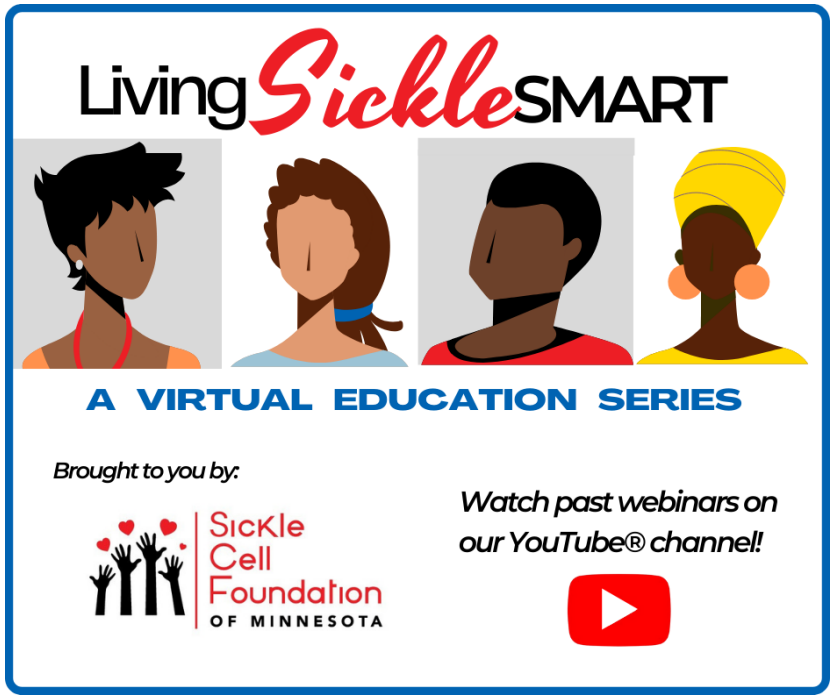
# SickleSMART Education Program

## YouTube Education Repository





www.youtube.com/@sicklecellmn

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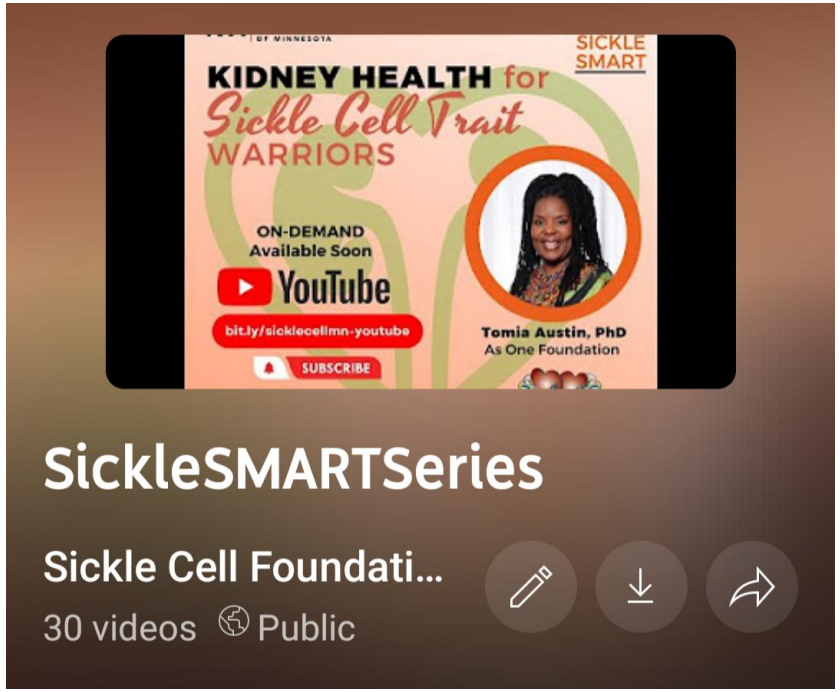
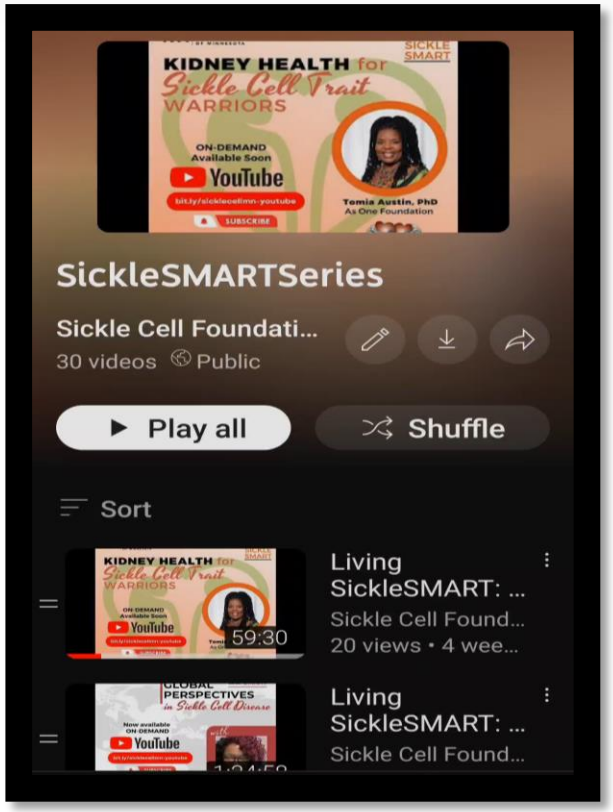
# YouTube Education Repository

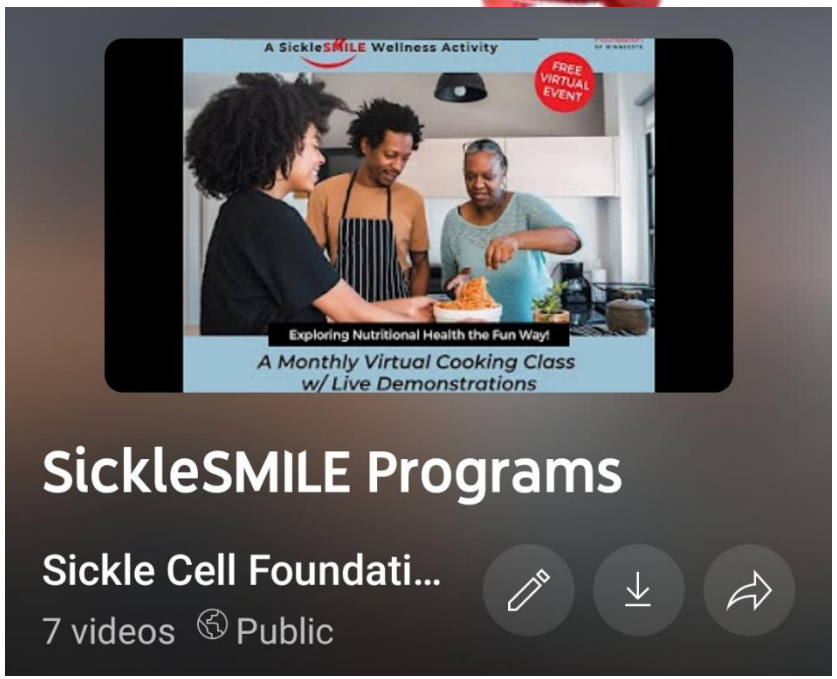
## On Demand Playlists




Living SickleSMART




www.bit.ly/sicklecellmn-youtube




SickleSMILE

Sickle Cell Foundation of Minnesota

# WHERE DO WE GO FROM HERE?











# Onward and Upward!


Supporting Us (:20)

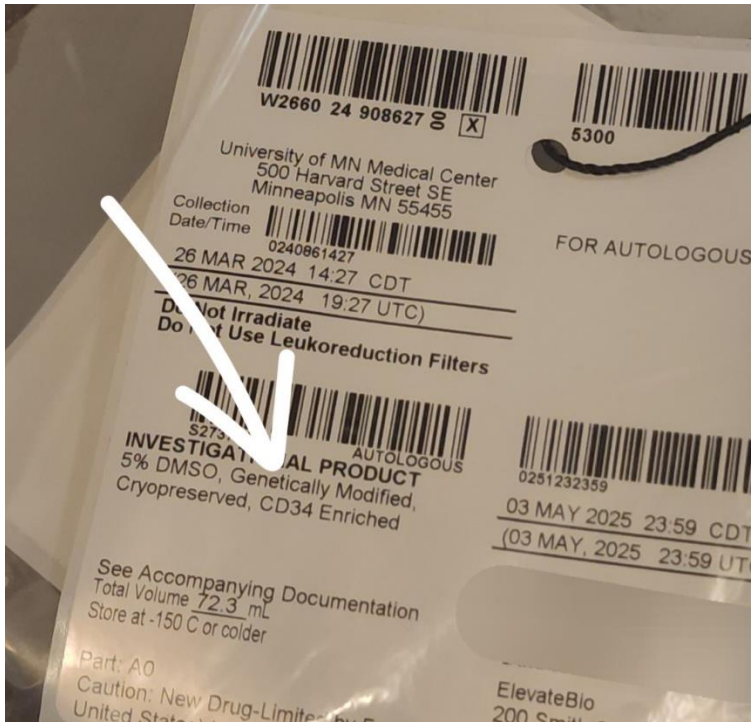
# HIS SUPACELLS

(Have you seen the Netflix series?)

## A New Beginning

## July 1, 2024

+




=


**please be gentle, I'm still learning.**

# TRUSTED GENERAL RESOURCES

**Nurses and other members of the medical team can assist individuals and families in navigating TRUSTED resources!**

- Books
- Websites
- YouTube
- Social Media
- **COMMUNITY-BASED ORGANIZATIONS (CBOs & PAGs)**

*Keep in mind that FB groups, group chats, and websites can be very helpful, some are not.

# PAPERS, ARTICLES AND CITATIONS


- **Improving the Lives of People with Sickle Cell Disease: Community Organizations and Epidemiologists Working Together (2024).** Young, A.J., Maresh, A., Pope, S., Blaylark, R., Lakshmanan, S., Stephens, L., Aderojou, R., Meier, E., Gibson, G., Okolo, A., Cromartie, S., Coker., Paulukonis, S., Fields, J., Kaur, M., Desai, J.
- **Finding Common Ground: a Pan-disease Advisory Council to Uncover Shared Unmet Needs in Hemolytic Anemias (2023)** *SCDAA. Arlington, VA, USA. Blaylark R*, Badalamenti N, Colasanti R, Colombatti R, Grace R, Jonassaint C, Kuo K, Levine L, Lobo C, Schryver T, Shah N, Sheth S, Trimnell C, Watson A, Welle J, Woolford T, John H, Davis J, Zaidi AU, Gallagher E, Gheuens S, Andemariam B.
- **Cross-Community Collaboration and Data Collection to Optimize Patient Care in Hemolytic Anemias (2023)**. 3692. *ASH. San Diego, CA, USA.* Andemariam B, Badalamenti N, *Blaylark R*, Colasanti R, Colombatti R, Grace R, Jonassaint C, Kuo K, Levine L, Lobo C, Schryver T, Sheth S, Trimnell C, Watson A, Welle J, Woolford T, John H, Davis J, Zaidi AU, Gallagher E, Gheuens S, Shah N.
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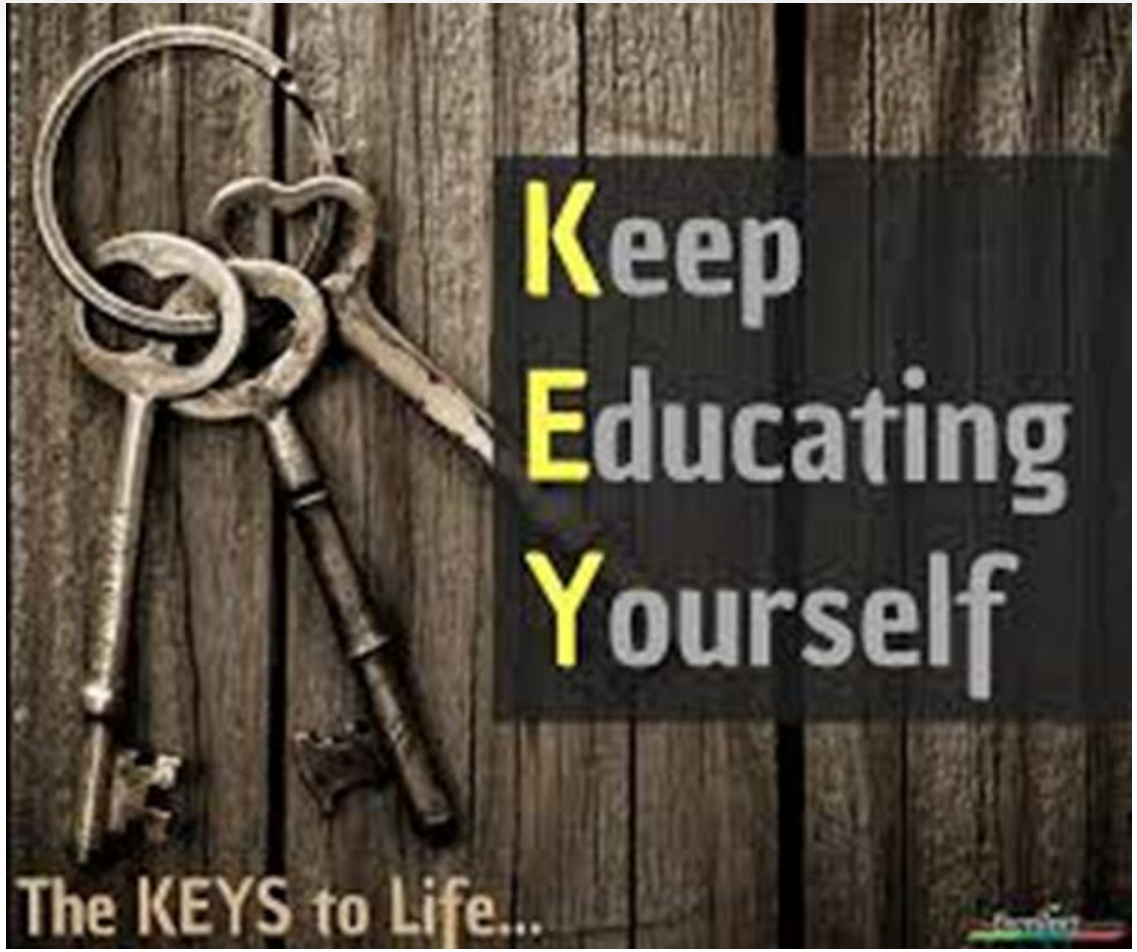
# KEEP LEARNING

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# QUESTIONS

www.sicklecellmn.org

# Thank You!


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# Highlights, accomplishments, and kudos!

In the chat, please add a key takeaway from today or a celebration you would like to share.

# Evaluation

# Thank You!

*The next Community of Practice will be announced in our newsletter.*
*Happy holidays!*

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